EVALUATING STRATEGIES TO ADDRESS QUALITY OF LIFE AND HEALTH-RELATED QUALITY OF LIFE AMONG CHRONICALLY ILL ADOLESCENTS IN THE INPATIENT SETTING

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ABSTRACT

Inpatient hospital stays can be isolating, especially for adolescents. Among those with one or more chronic illnesses, the average inpatient stay is between 5.4-9.3 days.(1) Support from peers can help mitigate stressors associated with feelings of loneliness and isolation.(2,3) The transition from childhood to adulthood is marked by developmental tasks that establish autonomy and identity.(4,5) The compounding stressors of managing a chronic illness and this period of development can be particularly challenging.(6-9) Chronically ill adolescents without a strong sense of identity are at higher risk for lower QoL than their peers.(10)

This thesis includes a summary of adolescents' predictors of QoL and HRQoL, which were categorized into seven distinct groups: demographics, use of coping skills, psychosocial factors, disease management and treatment, mental health status of the adolescent, mental health status of the caregiver, and physical environment. These seven categories were then used to examine the inpatient program offerings at 11 children's hospitals in the U.S.

Children's hospitals in the United States offer inpatient programs to address QoL and health-related quality of life (HRQoL) in various formats. Examples include visits from pet therapy teams, opportunities to create art, participate in exercise classes, and many other offerings. Many hospitals offer similar programs, and three of the eleven hospitals offer 1:1 peer support programs for adolescents with chronic illnesses.

UF Health Shands Children's Hospital in Gainesville, Florida (Shands) was selected as a case study. The hospital's 1:1 peer support program, Streetlight, is offered to chronically ill adolescents regardless of diagnosis and has been operational since 2006.(11) This thesis provides a qualitative analysis of patients', hospital leaders', and clinical providers' insights about inpatient support programs offered to chronically ill adolescents at Shands, with an emphasis on

the Streetlight program. This is done using interview data from patients who have been involved with Streetlight, and with healthcare providers, administrators, and staff at Shands.

This work has considerations for the ways hospitals and providers might approach enhancing QoL and HRQoL in the inpatient setting, as well as insights about the value of these types of programs for the healthcare team broadly.

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Cody and Carolyn,

Sitting at your bedsides changed the way I see the world. I am forever grateful for our friendship.

This is for you.

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CHAPTER 1. INTRODUCTION

1.1 Background

Inpatient hospital stays can be isolating, especially for adolescents. Support from friends is especially important for adolescents with chronic conditions, who, in addition to feeling lonely, often face challenging stressors associated with their medical condition, restrictions on personal activities, and demanding treatment regimens.(1) Peer connection and support can mitigate the impact of these stressors.(2,3) High levels of loneliness during adolescence are related to increased depression, more frequent visits to the doctor, and poorer self-reported health.(4) Without adequate psychosocial support, the compounding impacts of navigating both illness and normal adolescent development can make it more difficult for adolescents to adjust to life with a chronic disease.(5-8)

Adolescence marks the transition from childhood into adulthood and is a critical time for psychosocial development. Developmental tasks during this time help establish autonomy and identity.(9,10) Young adults progress through stages of forming peer groups, creating distance from parents (emotional and physical), establishing their physical appearance (e.g., clothes, hairstyles, etc.) and exploring school, hobbies and interests. In some cases, the demands of a teen managing a chronic illness can increase dependence on family and caregivers, at a time when it should be decreasing.(11) Adolescents and young adults who do not identify with peers and who are delayed in establishing a sense of identity may have significant psychological difficulties transitioning into adulthood.(9,12) In addition, chronically ill adolescents without a strong sense of personal identity are at higher risk for depressive symptoms and lower quality of life (QoL) than their peers with a stronger sense of identity.(13)

Children's hospitals face important decisions about how best to address the psychosocial needs of their inpatients. In an effort to create a more patient- and family-centered approach to care, some hospitals offer patients in the inpatient setting various activities that seek to enhance their QoL and pass the time. Examples include visits from pet therapy teams, opportunities to do arts and crafts, read books, listen to music, participate in exercise classes, and a suite of other options offered by social workers, volunteers, and/or in the case of children and adolescents, Child Life Specialists.

The extent to which hospitals offer these types of programs varies widely. Hospital leaders define operational priorities from a budgetary standpoint; funding decisions may be based on evidence showing a clear financial return on investment for the hospital. This thesis is not focused on estimating the financial return on investment. Hospital leaders sometimes approach decisions by seeking to understand if the initiative meets a patient need, and then, deciding if the need takes priority over other medical or non-medical initiatives that do not generate revenue. In order to make informed decisions about the breadth and scope of inpatient program offerings, leaders may consider assessing quantitative data and qualitative feedback from hospital providers, staff, patients, and their caregivers. This thesis provides a qualitative analysis of patients', hospital leaders', and clinical providers' insights about inpatient support programs offered to chronically ill adolescents.

1.2 Problem Statement and Gaps in the Literature

While adolescent health and care for individuals with chronic illnesses have an established literature,(14-17) there is a scarcity of literature that specifically discusses the impacts of offering psychosocial programs to chronically ill adolescents in the inpatient setting. Psychosocial health encompasses emotional, social, mental, and spiritual dimensions of health

and well-being. Healthcare providers, friends, and family members, play an important role in helping adolescents identify and implement strategies to improve their psychosocial health and enhance their QoL.

Inpatient hospital stays among children with one or more chronic illnesses average between 5.4-9.3 days.(18) Intensive, inpatient treatments may be necessary to treat and/or manage certain chronic illnesses. Examples include acute pain crises for patients with sickle cell anemia, surgery and early chemotherapy and/or radiation for adolescents with cancer, and pulmonary exacerbations for adolescents with cystic fibrosis.

While many hospitals seek to offer a variety of programs to help enhance patients' QoL, some hospitals may not be equipped to address psychosocial needs of adolescents who may struggle with the isolation of the inpatient stay in addition to facing other medical challenges. Psychosocial needs may be overlooked by physicians, nurses, social workers, and other providers who face mounting demands on their time.(19,20) In some cases, hospitals seek to refer and/or connect patients to programs available in the community. Some even utilize patient-centered medical home models that coordinate all aspects of the patients' care. These resources vary, and can include peer support groups, referrals to mental health counselors, and connections to non-profit organizations that might offer programs specific to individuals with certain medical conditions, for example. Depending on their circumstances, adolescents may have limited or no access to these external resources during their hospitalization. Sometimes this is, in fact, aligned with their plan of care which may prioritize acute medical needs. These resources are most often available to patients in the inpatient setting if they can be of assistance during the adolescent's transition from hospital to home. Even still, they may only be onsite at the hospital for a limited amount of time per week.

There is evidence that suggests current services are not meeting the needs of adolescents, who are often treated in pediatric or adult settings, where the tools and resources are either too young or too old from a maturity and development standpoint.(21-23) One of the main challenges is that the treatment regimens and emotional needs of adolescents vary widely between pediatric- and adult- clinical and behavioral-focused therapies.(21) Thus, adolescent patients benefit from care plans and treatment regimens that are more tailored to their circumstances.(21) In addition, adolescents may be less compliant with treatment plans, further necessitating a plan of care that is specific and considers the barriers that patients may be facing.(22)

There has been growing interest in the use of social support to provide adolescents with chronic illnesses opportunities to maintain relationships with peers and engage in social activities.(24,25) Peer support commonly refers to the development of a nonclinical, nonprofessional, helping relationship based on shared experiences and/or interests.(26,27) Peer support can be defined in a number of ways. Some peer support programs seek to inspire people recovering from illnesses or addictions, by pairing them with someone who has shared experiences. Others seek to provide self-help education and link people to resources and tools to help in their healing process. Others simply seek to support people in identifying their goals and dreams, and creating a roadmap to pursue them. Peer support for individuals with chronic illnesses typically centers on providing experiential knowledge – informational and emotional – in the journey to improving their quality of life. Peer support programs are offered in a variety of settings, depending on the approach. For some, support is done on a one-to-one basis, while others facilitate group support sessions. Support can be offered in person, over the phone, or online, for example. In some cases, peer support is offered in the inpatient setting.

Literature on the role of peer support in the inpatient setting is limited. The small amount of literature that exists is largely centered on peer support for adults with mental health diagnoses.(28-30) One study among adult psychiatric patients concluded that peer support was highly valued by patients, with themes centered on "responding to distress," "talking about personal stuff," and "we're stronger if we work together." The authors concluded that peer support should be a recognized aspect of an inpatient stay.(29) Another study found that adult patients with co-occurring substance use disorders and mental health diagnoses felt that peer support in the inpatient setting was a critical component of their return to the community, and that peer support should be incorporated into their treatment plan.(30) New research is needed to understand the extent to which peer support in the inpatient setting can be used as a strategy for individuals with chronic illnesses.

Hospital leaders participate in making decisions about the kinds of programs that will be offered to patients in the inpatient setting. There may be any multitude of factors that impacts their decisions, including: whether or not they believe a program meets a need among their patients, availability of funds, availability of data to measure process and outcomes metrics, patient and family feedback, insight from hospital providers and staff, and whether or not similar services are offered by peer institutions. More likely than not, decisions among leaders are informed by a combination of factors.

This thesis will review existing literature to understand adolescents' predictors of QoL and HRQoL. Next, interviews with patients, hospital staff, and hospital clinicians will be analyzed in order to understand the extent to which programs offered are addressing those predictors, and their perspectives on the extent to which the programs address them. Their

insights will illuminate the factors they consider to be most important in determining how programs address the needs of chronically ill adolescents in the inpatient setting.

1.3 Specific Aims

The following specific aims and hypotheses will be addressed:

Aim 1 seeks to define predictors of health-related quality of life (HRQoL) and quality of life (QoL) in general among adolescents with chronic illnesses. Based on a review of relevant literature that specifically focuses on adolescent well-being and self-reported predictors of QoL, categories of predictors will be gleaned and illuminated in detail. Research suggests children's hospitals may not be adequately addressing adolescent-specific challenges due to mounting demands on clinicians' time,(19-23) and the need to tailor adolescents' care plans often more deliberately than patients who are considered to be pediatric or adult exclusively.(21)

Aim 2 builds on these findings by first analyzing programs available at children's hospitals in U.S., focused on those programs that seek to enhance QoL by addressing the predictors identified in Aim 1. Based on the prevalence of chronic diseases in the U.S. by region, a recent study found the Mid-South population had increased rates of chronic disease when compared to the rest of the U.S. population.(31) This region had the highest percentages of obesity, diabetes, high blood pressure, and stroke, specifically.(31) Given that the prevalence of chronic illness follows individuals throughout the life course, the management of and prevention of chronic conditions in children and adolescents has the ability to reduce unnecessary healthcare utilization and maximize health outcomes.(32) Noticing the increased prevalence of chronic disease in the South,(31) the analysis targets the offerings of children's hospitals in the southeast region. Information about the programs will be categorized according to these predictors. Information about programs at the 11 children's hospitals will be gathered from publicly-

available information on the hospitals' websites and via telephone conversations with staff at the hospitals who will review and refine the information gathered in order to provide an accurate summary.

In addition, Aim 2 examines the Streetlight program at University of Florida (UF) Shands Children's Hospital in Gainesville, Florida. Streetlight was identified in Aim 2 as being a 1:1 peer support program that seeks to address predictors of HRQoL for adolescents at the bedside. Notably, two other programs, at the University of North Carolina Children's Hospital and Wolfson Children's Hospital, offer similar 1:1 peer support programs, though neither program is specific to adolescents. In addition, the program at UNC Children's Hospital is specific to hematology/oncology patients only. While the program at Wolfson's Children's is not disease-specific, it has only been operational for one year, whereas Streetlight has been in operations for 14 years. Given these differences, Streetlight was selected for closer analysis. This analysis offers a qualitative evaluation of patients' perceptions of the Streetlight program's impact on addressing predictors of QoL focused on coping skills, psychosocial factors, and the adolescents' mental health status.

Aim 3 will examine the Streetlight program's strengths and weaknesses from the perspective of hospital administrators and healthcare professionals at UF Health Shands Children's Hospital. This aim will focus on perceptions of the program's operations (i.e., process for making referrals, overlap with other hospital services) as well as perceptions about the program's ability to address psychosocial needs of the patients served. These findings will inform a discussion about whether or not the program, or certain aspects of it, should be considered for replication and/or scaling purposes. Findings will also contribute to a discussion of policy and practice implications.

1.4 Dissertation Organization

This dissertation is organized in the three-manuscript format and is divided into five chapters. Chapter 1 provides the introduction of the dissertation including background on adolescents with chronic illnesses, the problem statement and gaps in the literature, specific aims of the thesis, and the overall organization of the thesis. Chapter 2 (Manuscript 1) is a review of relevant literature, specifically focused on predictors of QoL for adolescents who have one or more chronic illnesses. Chapter 3 (Manuscript 2) provides a detailed summary of the inpatient offerings available to adolescents at a sample of children's hospitals in the southeast US. Comparison of programs at 11 children's hospitals will offer insight into the landscape of program offerings broadly, which may illuminate the extent to which hospitals are dedicating specific resources to address these needs in the inpatient setting. Included in Chapter 3 (Manuscript 2) is a qualitative analysis of patients' perceptions of one such program, Streetlight.

Chapter 4 (Manuscript 3) provides a qualitative analysis of hospital provider and leaders' perceptions of Streetlight. Chapter 5 is a summary of the findings and a discussion of the policy and practice implications related to this work. This includes conclusions about the similarities and differences between patients' and providers' perspectives about a 1:1 peer support program, as well as providers' insights about how to approach discussions around the value of these types of programs with hospital leaders.

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CHAPTER 2. PREDICTORS OF QUALITY OF LIFE AND HEALTH-RELATED QUALITY OF LIFE AMONG CHRONICALLY ILL ADOLESCENTS

ABSTRACT

Background: The first part of this chapter reviews relevant literature related to predictors of QoL and HRQoL for adolescents with one or more chronic illness. The intention is to describe the existing evidence base of these predictors and to identify where there is consensus and disagreement in the literature and to identify gaps in the literature.

Methods: The scoping review summarizes peer-reviewed articles that met certain search criteria within Scopus, the largest abstract and citation database of peer-reviewed literature. The search terms included: predictor(s), adolescent(s)/adolescence, chronic illness(es)/chronically ill, quality of life, and health-related quality of life. To narrow the results of the search, each article needed to contain all of the listed search terms. The search also specified that articles must be published in English. The search was not limited to programs in the U.S., as this was restrictive on the number of results returned in the initial search. Of those meeting necessary inclusion criteria, all referenced articles therein were also reviewed.

Results: The literature synthesis revealed various predictors of QoL and HRQoL specific to adolescents with one or more chronic illnesses. These predictors are categorized into seven main themes: demographic characteristics, use of coping strategies, psychosocial factors, disease control/management, mental health status of the adolescent, mental health status of the caregiver, and the physical environment.

Conclusions: Among the seven categories, the majority of predictors of the adolescent's QoL are attributed to four categories: the use of coping strategies, psychosocial factors, disease management and treatment, and the mental health status of the adolescent. Hospitals should

consider whether the services available to chronically ill adolescents in the inpatient setting address these categories of predictors, with specific attention to the use of coping strategies, psychosocial factors, and mental health, as hospitals are already likely seeking to deliver high-quality disease management and treatment.

Keywords: adolescent, teenager, psychosocial, well-being, chronic illness, chronically ill, palliative care

Running Title: Predictors of HRQoL among Chronically Ill Adolescents

2.1 Background

Medical and public health innovations in the 20th century have led to striking changes in the diagnosis and treatment of chronic health conditions. In 1960s, less than 2% of children had health conditions that disrupted their daily activities.(1) In 2010, it had risen to more than 8%(2), an increase of more than 400% over 5 decades. The rise is attributed largely to asthma, obesity, mental health conditions, and neurodevelopmental disorders.(3)

As rates of chronic health conditions among youth have steadily increased, survival rates for many chronic conditions have improved.(3) Over 85% of children with chronic conditions now survive into adolescence.(4) Eighty-five percent of girls and 80% of boys are still alive 5 years after being diagnosed with cancer.(5) Adolescent cancer survivors are more likely to have worse or impaired QoL compared with the general population.(6) Intensive, inpatient treatments may be necessary to treat and/or manage certain chronic illnesses. Examples include acute pain crises for patients with sickle cell anemia, surgery and early chemotherapy and/or radiation for individuals with cancer, and pulmonary exacerbations for patients with cystic fibrosis. The average inpatient hospital stay among children with one or more chronic illnesses ranges between 5.4-9.3 days.(7) Regardless of the length of their admission, they may experience periods of frequent, repeated inpatient stays depending on their circumstances. This can impact their QoL and HRQoL.

Inpatient stays can be isolating and lonely. For children and adolescents with chronic illnesses, loneliness is associated with disease-specific correlates, including cardiac symptoms(8) and poorer adjustment to illness.(9) Managing a chronic illness in adolescence can impact physical, social, cognitive, and emotional aspects of ones' life.(4)

QoL refers to someone's satisfaction with all aspects of life, including physical, social, economic, and psychological well-being. HRQoL, while similar, specifically describes the impact of health on someone's overall well-being.(10) Assessing QoL may help to evaluate interventions or programs of care, whereas assessing HRQoL can help illuminate the aspects of an individual's life that are influenced by their disease, treatment, and/or care. Measurement of HRQoL typically includes assessment of physical health, psychological health, social functioning, and general health perceptions. This literature synthesis seeks to address both domains so as to gain a broad understanding of all possible predictors of an adolescents' overall well-being. In order for hospitals and healthcare providers to appropriately and adequately address these issues, there is a need to identify adolescents' predictors of both QoL and HRQoL from evidenced-based studies.

Adolescence is a period of life marked by identity formation and development of autonomy. This transitional period of physical and psychological development is characterized by improvements in knowledge, abstract thinking and reasoning, as well as physical changes resulting from puberty.(11) Young adults progress through stages of forming peer groups, creating distance from parents (emotional and physical), establishing their physical appearance (e.g., clothes, hairstyles, etc.) and exploring hobbies and interests. This is also the period when individuals might begin to explore their sexuality or pursue romantic relationships.

Social isolation, or loneliness, during adolescence may manifest in an absence of social relationships or contact with others. An individual's social life changes and develops rapidly during adolescence.(12) During this time, youth spend less time with family members and more time with peers.(12) As this shift occurs, youth revise their own views about what it means to be alone. In fact, some might perceive time spent with parents or family members as social

isolation.(12) Among adolescents who regard the absence of peer contact as evidence of unpopularity, feelings of isolation might be intensified.(12)

Children's hospitals offer a wide range of programs to help make the inpatient setting more pleasant. These include, for example, services offered by certified Child Life Specialists, palliative care teams, volunteers offering alternative therapies with pets and music, and a wide range of other services. While many hospitals seek to offer a variety of programs to help enhance patients' QoL, some hospitals may not be equipped to address psychosocial needs of adolescents. Moreover, some hospitals may not offer programs that address issues around social isolation. Given the reality that adolescents with chronic illnesses may experience long inpatient stays, frequent shorter stays, or even infrequent stays altogether, it is important that hospitals recognize the impact of social isolation during adolescence. Further, as discussed, the impacts of social isolation during adolescence may be exacerbated by the challenges adolescents face in managing their chronic illness and the social and societal struggles they encounter as a result of their illness.

2.2 Methods

Design and Setting

The scoping review summarizes a subset of peer-reviewed articles that meet certain search criteria within Scopus, the largest abstract and citation database of peer-reviewed literature. Specifically, this synthesis draws out the predictors of QoL or HRQoL for adolescents with one or more chronic illness. The intention is to describe the existing evidence base and to identify gaps in the literature. This is intended to be a comprehensive, but not systematic review. The search will be complete when no new predictors of QoL or HRQoL are revealed in the articles.

The search terms included: predictor(s), adolescent(s)/adolescence, chronic illness(es)/chronically ill, quality of life, and health-related quality of life. Because of the overwhelming amount of literature specific to each of these keywords individually, this search strategy was built to include the Boolean operator "AND" between each keyword, seeking articles that referenced all of the keywords, rather than 1 or more. The search was limited to articles published in English. The initial search returned 49 articles. Of these, 17 met necessary inclusion criteria for the literature review. Thirty-two articles were excluded for various reasons, including: the article was not assessing predictors of QoL or HRQoL, the study was not specific to adolescents ages 13-21 and/or did not have results specific to that age range, subjects were not self-reporting information, and the article was a commentary or study based on tool validation. Refer to Table 1 and Figure 1. Given the pivotal shift of transitioning from childhood to adulthood, and the role that establishing independence and autonomy plays during this time, self-reported information from adolescents is most desirable. It will also help to reduce any bias from parents or caregivers who may have otherwise spoken for the adolescent about what they feel predicts the adolescents' QoL.

All references from the initial 17 articles (754 total, 701 after removing duplicates) were then assessed for inclusion, and 171 met necessary inclusion criteria. Refer to Figure 2. In total, the 17 initial and the 171 additional studies were included in the literature synthesis (total = 188). Refer to Figure 3.

Of the 701 referenced articles, 530 were excluded for various reasons, including: the article was not assessing predictors of QoL or HRQoL, the study was not specific to adolescents ages 13-21 and/or did not have results specific to that age range, subjects did not have at least one chronic illness, subjects were not self-reporting information, the study was not focused on

the needs of the adolescent patient, the article was not a study but rather a commentary, survey tool, or other instrument, or the article was not available in English, among other reasons. The span from ages 13-21 was based on the American Academy of Pediatrics' classification of stages of adolescence, which includes early adolescence (ages 10-13), middle adolescence (ages 14-17), and late adolescence (18-21).(13) Only the upper end of the early adolescence period was included in this span, as early adolescents tend to have more concrete, black-and-white thinking,(13) and this scoping review seeks to understand nuances around perceptions of QoL and HRQoL. Refer to Table 2.

In reviewing and synthesizing the literature, predictors of QoL or HRQoL were extracted from articles, amalgamated into a master list, and grouped together with other same or similar concepts, to form categories. Refer to Table 3 for the predictors organized by category. Many studies identified more than one predictor. Refer to Table 4 for the predictors identified, by study.

2.3 Literature Review

This thorough review revealed a variety of predictors of QoL and HRQoL, as identified in studies that surveyed adolescents with at least one chronic illness. Studies were generally specific to a population of adolescents with a specific condition or diagnosis, such as cancer, sickle cell disease, diabetes, and cystic fibrosis, though some were broadly focused on populations of chronically ill adolescents. Studies were included in the review if they met the inclusion criteria, including that the adolescent had self-reported their QoL or HRQoL as opposed to a caregiver reporting on their behalf.

Categories of Predictors

A review of all 188 articles included in the analysis revealed common "categories" of predictors. These groups include predictors specific to: demographic characteristics, the knowledge and use of coping strategies, psychosocial factors, characteristics of disease control and management, the mental health status of the adolescent, the mental health status of the caregiver, and the physical environment. The sections below provide a more in-depth review of predictors in each category.

The review followed a methodical and organized approach to evaluate each article. First, articles were reviewed to ensure they met the eligibility criteria for inclusion. These include being published in English, availability of full-text articles (as opposed to articles not held by libraries or databases or PhD theses unavailable to the public), assessing predictors of QoL or HRQoL for the adolescent, being specific to adolescents between the ages of 13-21 or reporting results by age if spanning all pediatric groups, including participants with one or more chronic illness, study participants self-reporting predictors (as opposed to caregivers serving as a proxy), and studies that were done to report findings (as opposed to those done for tool validation or scale development, for example).

Once determined eligible for inclusion in the review, each article was carefully examined. Refer to Table 4. This process included creating a spreadsheet, first listing the article's title, authors, year published. Next, each article was read in detail, to examine whether the study determined specific predictors of QoL. If results were inconclusive about a potential predictor or if a predictor was determined to be not significant ($p>0.05$ in statistical analysis), it was not included as a predictor of QoL in Table 4.0. Each predictor was listed as it was written verbatim in the article.

Finally, the predictors were organized into a table, similar to Table 3.0, without the top row. Similar predictors or those that appeared to be linked to the same area or category were grouped together vertically. Predictors were only listed once, even if mentioned multiple times in the review. At the end of this process, the top row was added and the categories were named according to the broader category representing all of the predictors in the column. Refer to Table 3.0.

Demographic Characteristics

The studies revealed that a number of demographic characteristics contribute to overall QoL or HRQoL. Among chronically ill adolescents, demographic predictors included age at diagnosis,(14-19) age at treatment,(20,21) gender,(15-18,22) height,(23) family income,(16,24) socioeconomic status,(25,26) birth weight,(23) type of insurance,(14,27) family structure,(17) and maternal education.(20) Among the 188 articles, 23 articles cited one or more demographic predictors of QoL.

An individual's given health and social circumstances have impacts across the life course.(28) The whole-person approach to developing a plan of care that will address an individual's situation can be challenging. Certain characteristics, such as maternal education and socioeconomic status theoretically could be addressed with an intervention or supportive services, whereas height and age at diagnosis, for example, are out of the control of the adolescent, their caregivers, and the care team. While it is difficult to design interventions or offer services to address all demographic characteristics, their role in the landscape of predictors should not be diminished. Certainly, the social history of patient is captured and available to providers as part of the patient's medical record. Providers and healthcare institutions should

consider how and when this information is reviewed, especially among chronically ill adolescents, in order to effectively address potential issues related to their QoL.

Family support plays a significant role in this population.(29-31) In this review, a single-parent family model was associated with decreased QoL.(17) Engagement of caregivers in the care planning process helps adolescents feel supported.(32,33) A higher family income was also associated with increased QoL,(16) given fewer financial stressors placed on the family. Lower maternal education was also predictive of decreased QoL among adolescents.(20) In some instances, a family's focus can be spread thin between various challenges, thus having to choose how to prioritize their resources. A chronically ill adolescent may attend treatments or appointments alone, for example, if their caregiver(s) is not able to step away from work. A hospitalization may be socially isolating for an adolescent whose family members and friends are not able to be at the bedside.

Use of Coping Strategies

An adolescent's use of coping strategies was also illuminated as being predictive of QoL or HRQoL. Some studies looked at specific coping strategies,(34,35) while others asked adolescents to report more broadly about their knowledge and use of coping strategies when faced with pain(36-38) or emotional distress.(39,40) Among the 188 articles, 40 articles cited the use of coping strategies to be a predictor of QoL or HRQoL.

Coping strategies describe an individual's conscious effort to address personal and interpersonal problems in response to stress or discomfort.(41) Coping styles and strategies are specific to the individual, and are often categorized as being either emotionally-focused or solution-focused. That is, the strategies are seeking to comfort, alleviate, or mollify discomfort, or they are intent on changing the given circumstances. Not all coping strategies are considered

to be healthy and effective. Regardless, individuals employ coping strategies based on their lived experiences, learned behaviors, and mental health status.(42-44) Licensed mental health professionals seek to understand patterns around an individual's coping strategies, and will often try to guide or steer individuals toward coping strategies that are healthiest. Adolescents with chronic illnesses may or may not be able to change the circumstances surrounding their disease(s). Most of the coping strategies that were found to predict increased QoL or HRQoL were emotionally-focused (refer to Table 3).

Coping strategies such as distancing oneself from the disease or accepting the fact that they have the disease were found to be predictive of enhanced QoL among adolescents.(42,43,45) In addition, many articles cited the use of spiritual and religious practices such as prayer, as being helpful to some adolescents. Wishful thinking and spiritual meditations were also found to help center some adolescents, easing the burden of their illness by helping them to focus on the present moment as opposed to thinking about the future.(34,46,47)

Adolescents with chronic illnesses have been found to practice self-focused coping, which refers to the tendency to be more aware of the information internally generated than externally generated.(48) In other words, the need and desire for an adolescent to focus on monitoring their condition can lead them to obsess over information they generate internally which may not be true. Among healthy adolescents, high levels of private self-focus are associated with depression.(49)

The use of cognitive behavioral therapy (CBT) is yet another strategy that has shown to be predictive of QoL among chronically ill adolescents.(50,51) Licensed therapists who utilize the CBT technique often tailor sessions to working with their client to identify coping strategies to address depression, anxiety, and post-traumatic stress disorder, for example. Participation with

a licensed therapist is its own form of coping strategy as well. Some adolescents utilize therapy as a strategy to cope with persistent pain.(38,50) This will be explained in more detail in the category of predictors focused on the adolescent's mental health. Adolescents who may be more socially isolated utilize therapy as a way to connect with someone who is a good listener and who can assist them in talking through their emotions.

Finally, two studies examine another predictor of QoL known as locus of control.(41) Adolescents with an external locus of control are more likely to associate their successes or failures with factors beyond their control – such as fate, luck, circumstance, etc. The opposite of this is an internal locus of control, or the sense that they have more control over their environment and the situation at hand, perhaps including their treatment. Internal locus of control is predictive for better illness-related adjustment in adolescents.(52)

Psychosocial Factors

Psychosocial factors include an individual's interpersonal relationships and social environment. They are predictive of QoL and HRQoL in that they affect an individual's physical and mental wellness, as well as their ability to navigate everyday life. Among the 188 articles included in the review, 61 articles cited psychosocial factors as predicting QoL or HRQoL among chronically ill adolescents. This category had the most diversity in predictors. Smaller sub-groupings of these predictors include: social and emotional support, school participation, family dynamics, navigating other peoples' perceptions, dating and romance, and identity and independence.

Predictors that appeared repeatedly included those specific to an adolescent's ability to attend and participate in school activities.(37,53-59) This includes the daily rhythm of going to school as well as interacting and socializing with peers.(57-59) School participation provides

adolescents the opportunity to engage in activities that can build self-esteem and help to establish peer relationships. Adolescents who are managing a chronic illness can learn to do so in a learning environment, away from their caregivers and medical providers.(60) In a study focused on adolescents with asthma, poorer asthma-specific QoL was associated with missed school.(57) Academic achievement, and consistency in school performance, can be difficult for adolescents with chronic illnesses due to extended and unpredictable absences due to their health.

Another grouping of psychosocial predictors centers on social supports available to the adolescent and their family. One particular study of adolescents with and without asthma found that support available to the family was predictive of better psychological adjustment of the adolescent.(61) In addition to the family being supported by others, adolescents reported that, to them, a supportive family and friend group predicted various measures of their own well-being.(62) Further, involving friends in their care and treatment regimens helped to buffer the impact of stressors, such as adjusting to coping with their disease.(63) Adolescents who reported high levels of support from both family and friends exhibited fewer behavioral problems than adolescents who felt they only had support from one source.(63) The use of social networks as a way to interact with peers and engage online has also been shown to be a major factor influencing adolescents' QoL.(15)

Another set of predictors centered around family and parental dynamics, including interpersonal relationships within the family, the support and warmth of the family, and the family's ability to adapt to changes that need to be made as a result of the adolescent's illness.(23,31) One study found that among adolescents who reported chronic headaches as a symptom, the family's daily routine significantly impacted both their ability to cope and their QoL.(31)

Finally, psychosocial predictors also include the public's perception of the illness, including the anxiety that adolescents might have in talking about their illness with friends. Among adolescents with sickle cell, one study found that an inability to play games with friends (due to their illness) led them to be unhappy.(64) Further, the sense of shame they had in public for having this illness in general was also a reason given for their unhappiness.(64)

Disease Presence/Control/ Management

Among the 188 articles included in the review, 81 articles cited factors related to disease presence, control and management as predicting QoL or HRQoL among chronically ill adolescents. This category had the highest diversity among predictors, ranging from the number of medications they were juggling, to reported pain, stiffness, and fatigue, to the intensity of the treatment regimen they were following. Most specifically within the category, however, the presence of and ability to manage pain was cited many times as predicting QoL.(36,65-67) Pain was consistently referenced in articles that overlap a number of categories. For example, debilitating pain might affect an individual's mental health, or even that of their caregiver. It may also impact psychosocial factors such as the ability to be involved in activities with peers. Pain, and the management of pain, are a significant predictor of QoL.

At baseline, having a chronic condition, the type of chronic condition, and presence of comorbid diseases and symptoms, were all predictive of QoL.(68,69) The extent of disease and disease severity were also associated with decreased QoL.(70,71) This may be due to limitations on the adolescent's independence and mobility, among other factors. Moreover, the treatment regimen for an adolescent's condition also predicts QoL.(72,73) Specifically, difficulty following the regimen or a clinician's observation of "nonadherence" was associated with decreased HRQoL in one study that included pediatric patients who had undergone a liver

transplant.(73) The study results indicated that nonadherence was specifically associated with decreased physical HRQoL, as well as more limitations in social and school activities.(73) The association between adherence and HRQoL is particularly important among adolescents who have received a transplant, as medication regimens, consistent clinic appointments, and other activities that require patient and family engagement are critical to the success of the transplant process.

An adolescent's satisfaction with their treatment is predictive of their QoL.(40,74) High levels of treatment satisfaction were associated with positive QoL among adolescents with early-onset type 1 diabetes.(74) The results of one study indicated that in addition to satisfaction, other modifiable disease-related factors such as glycemic control and insulin therapy had impacted QoL.(74) The authors concluded that further enhancement of diabetes care, including individualized psychosocial support, would be needed to improve QoL among patients managing complex and demanding therapies.(74)

Studies also found that the presence of psychosomatic symptoms predicted a decreased QoL.(22,75) Psychosomatic symptoms include pain, fatigue, headache, difficulty concentrating, and other factors that cannot be medically explained. Some of the symptoms are more directly related to physical health (i.e., stomach aches, headaches, dizziness) and others are more aligned with an individual's mental health and well-being (difficulty sleeping, difficulty concentrating, depressive symptoms, etc.). Hence, some of the predictors are also categorized in the "mental health status of adolescent" category. One study examined the association between psychosomatic symptoms and HRQoL across age and gender and found that boys and girls ages 11-12 rated their HRQoL more highly than older adolescent boys and girls.(22) Further, girls and adolescents reported lower HRQoL than boys and younger children, respectively.(22) The

authors examined and discussed the role that age may play in impacting HRQoL, concluding that pubertal processes are likely responsible for the different levels of HRQoL in the study.(22) They also reported that depression and concentration difficulties were associated with HRQoL among girls, and stomach aches were associated with HRQoL among boys.(22) Their findings suggest that studies of HRQoL may be of great significance in understanding adolescents' development in the context of their perceptions of illness and disease.

Yet another predictor of QoL includes issues surrounding medical transitions. This includes transitions from pediatric to adult care,(76) and learning to manage a chronic condition in a college setting, after leaving home.(77) One of the reviewed articles found that students with a chronic illness had lower HRQoL and higher loneliness scores as compared to healthy peers.(77)

Finally, another predictor that was cited in the review was emergency department (ED) visits. One study surveyed youth with types 1 and 2 diabetes, and found that having two or more ED visits within 6 months was associated with poorer HRQoL.(27) Interestingly, among the same population, HRQoL was lower for girls and higher for boys.(27) Another study examined QoL among adolescents with asthma, and also found QoL was poorer with increased ED visits.(57)

Mental Health Status of Adolescent

Among the 188 articles included in the review, 76 articles cited mental health status as predicting QoL or HRQoL among chronically ill adolescents. This category has the second highest variability in predictors among the seven categories.. The effects of this stage of life are compounded for adolescents who are also navigating a chronic illness. Articles reviewed discussed the role of self-esteem,(58,78-80) body image,(81) and life satisfaction(82) as

predictors of QoL. Other common predictors were depression,(14,22,43,83) anxiety,(43,53,84,85) beliefs about the illness (i.e., my illness makes me different than other people),(86) and distress from illness uncertainty.(53,87,88) Some adolescents reported that dating anxiety negatively impacted their QoL.(89) Fear of physical intimacy and fear of negative evaluation (i.e., not being desirable) were the reasons adolescents reported reduced QoL as compared to healthy peers, in one study.(89)

Mental Health Status of Caregiver

Among the 188 articles included in the review, only five articles cited the mental health status of the caregiver(s) as predicting QoL or HRQoL among chronically ill adolescents. It is noteworthy to mention that, in these studies, the caregiver's mental health status may or may not be related to the adolescent's chronic condition. For example, the stress that can be present in divorced and single-parent families may greatly impact an adolescent. An individual's marital status and whether or not they feel supported may also affect their ability to cope with challenges of their child's illness. Additionally, issues such as financial strain and employment could similarly impact a caregiver's mental health.

One study found that among cancer patients, better parental adjustment (measured using the Brief Symptom Inventory self-report questionnaire) was associated with better HRQoL for the patient, particularly in the emotional domain.(69) Another study examined the parent-child adjustment relationship among adolescents with juvenile rheumatic disease, and found that increased parental distress was associated with greater depressive symptoms in the child.(19) There is still much that is not well understood about the importance of parental and familial variables on an adolescent's HRQoL. Further studies might help to illuminate ways to design family-based interventions to support chronically ill adolescents.

Physical Environment

Among the 188 articles included in the review, only one article cited the physical environment as predicting QoL or HRQoL among chronically ill adolescents. More specifically, the article reported that a change in seasons affected comorbid seasonal allergies for some adolescents with chronic illnesses.(90)

2.4 Discussion and Conclusions

Themes

The seven categories identified could be further grouped into themes to help healthcare leaders prioritize how they might address predictors of QoL. For example, these seven categories could be split into two themes: 1) those for which an intervention could be offered (i.e., psychosocial factors, use of coping strategies, disease management/treatment, mental health status of the adolescent), and 2) those which are more out of the control of the patient and/or their providers (i.e., demographic characteristics, mental health status of caregiver, and physical environment). This process might help to distill the information in more manageable terms, when thinking about how and where to allocate resources. Other groups of themes might include 1) categories that address an adolescents' emotional/mental health and well-being (i.e., use of coping skills, psychosocial factors, mental health status of adolescent) and 2) those that address their physical health (i.e., disease management and treatment). Another set of themes might be 1) categories of predictors for which adolescents are more in control (i.e., use of coping skills, psychosocial factors, mental health status of adolescent), 2) categories for which providers are more in control (i.e., disease treatment and management, mental health status of the caregiver), and 3) categories of predictors which are difficult for stakeholders to control (i.e., demographic characteristics, physical environment). Healthcare institutions, medical providers, and other

organizations that seek to address matters related to patients' QoL and HRQoL might find it useful to utilize these groupings for purposes of prioritization. If developing a strategic plan for the hospital, for example, they might decide to pilot interventions focused on emotional health and well-being in years 1-3, and then pilot interventions to address physical health in years 4-5.

Approaches to healthcare prevention and treatment are increasingly focused on supporting patients and families with a more whole-person approach. Notably, the inclusion of the importance of mental health alongside physical health has gained traction in the past decade. Increasingly, healthcare institutions, insurers, and healthcare providers are drawing attention to the importance of overall well-being. As researchers uncover new information about the impact of predictors on QoL, and as adolescents are given the chance to vocalize their needs, stakeholders may pay more attention to how to integrate related supports into the standard of care.

The mental health and well-being of chronically ill adolescents has the potential to improve, perhaps more than their physical health in some cases. This category of predictors is important to consider in the development and offering of resources to assist patients navigating a chronic illness. This category represents factors for which adolescents and their care teams can devise strategies to address diminished QoL. Strategies that focus on developing resilience,(91) increasing psychological flexibility,(92) and addressing cognitive and emotional issues(93) should be considered, given that studies have found they predict QoL among chronically ill adolescents.

While there were no disagreements in the literature, some predictors of QoL for chronically ill adolescents were found to be more or less significant for the population in the study than others. This seemed to be based mostly on the adolescents' diagnosis and the extent to

which symptoms of their illness impacted their daily routines. Hospitals and healthcare providers may want to understand if adolescents with specific diagnoses might benefit more from addressing certain predictors of QoL.

Though it only appeared only once in this particular literature review, the physical environment would be interesting to more closely examine how the physical environment impacts an individual's quality of life, especially if they are also managing a chronic illness. This could have implications for the environment created for patients by hospitals, including that of their inpatient room and other locations throughout the facility.

Actionable Predictors of QoL and HRQoL

The categories are distinct, each representing a unique line of insight into the perspective of an adolescent coping with a chronic illness. When thinking about interventions that might be offered to enhance QoL, some of these categories are not easily actionable, at least in the present. Demographics, such as the teen's birth weight and age at the time of their diagnosis cannot be changed. Hospitals and healthcare providers might be especially interested in the categories that represent predictors for which there are ways to address the issue. These categories include helping adolescents develop coping strategies, addressing predictors of the adolescent's mental health and that of their caretakers, devising interventions around psychosocial predictors, and working with the healthcare team to manage the adolescent's disease. These represent actionable categories for which predictors of QoL or HRQoL could be addressed.

Gaps in the Literature

The literature included in this review is focused on adolescents with chronic conditions, regardless of whether their care is provided in the inpatient setting, outpatient setting, or a combination of the two. As discovered in this review, more research is needed to understand

adolescents' predictors of QoL in each setting independently. This might help hospitals and healthcare providers tailor interventions according to the setting in which the patient is being treated. In addition, the setting in which the adolescent is responding to a QoL survey or questionnaire may also impact their responses. It would be important to compare, for example, how adolescents might report differences in predictors of QoL if answering a survey while undergoing treatment in the inpatient setting versus reflecting on that treatment years later when they are managing their condition on their own, with regular appointments in the outpatient setting. Adolescent perceptions about inpatient care are also likely influenced by the extent to which outpatient providers address psychosocial needs and well-being.

An interesting aspect of care for chronically ill children is the reality that they will, at some point, transition to adult care. These transitions can be marked by nervousness and anxiety for patients and their families.(77) The American College of Physicians has developed the Pediatric to Adult Care Transitions Initiative, which is a collaborative effort to develop a toolkit to help facilitate more effective transitions for young adults.(76) Existing literature also supports the notion that these transitions can be stressful for healthcare providers and care team members.(76) Further examination of the impact of QoL and HRQoL predictors and the role they play in these transitions would be critically important in helping to assess the readiness of the adolescent as well as the care team. There are tools, for example, to assess the extent to which adolescents have developed certain coping skills, or even to determine whether their mental health state (or that of their caregiver) is prepared to support a transition. With more insight into how predictors of QoL impact medical transitions, more effective systems could be established to ensure the adjustments are as smooth as possible.

Another area for further investigation would be whether the role of distraction impacts QoL, and whether some adolescents might be better positioned to develop or utilize this kind of strategy. For example, some hospitals offer pediatric patients the opportunity to play games, watch movies, and read books during their inpatient stay or treatment session. Some also offer activities and games, which can be led by a hospital volunteer. It would be interesting to understand the effect of distraction versus mindful acceptance as a coping strategy for adolescents. It might be beneficial to consider a range of strategies to more precisely target an adolescents' readiness, needs, and priorities.

Limitations

The initial search, using the search terms described above, returned a total of 49 articles. Of these 49 articles, 17 met the criteria to be included in the review. When the search was initially conducted with these search terms, thousands of articles were identified, many that were not specific to adolescents, chronic illness, or quality of life. Given this, the Boolean term "AND" was used to seek articles that included all of the search terms as opposed to simply finding those with 1 or more. The number of articles returned in this initial search was low, which led to a close review of the included search terms and journal databases with an information specialist at the Johns Hopkins Bloomberg School of Public Health. Seeing as the search terms were well-representative of the desired literature, and based on the types and volume of journals contained within Scopus, it was decided to use this methodology and include all articles referenced in the 17 articles found to be eligible for inclusion after the initial search. This ultimately led to a review of 718 total articles for this synthesis. It is possible the method utilized may have excluded articles on this topic.

Most of the studies included in the review assessed adolescent's predictors of QoL at a single point in time, such as during hospitalization or at the time of diagnosis. Because these time stamps were not consistent across all included articles, it can be difficult to compare results across studies and chronic conditions. It is also challenging to identify whether there might be a timing component to adolescents' QoL-related predictors. If, for example, QoL was particularly low during inpatient stays, for example, hospitals may wish to focus their efforts on offering inpatient programming. Having this information might be helpful to healthcare providers and family members, who may be seeking opportunities to support the adolescent in the inpatient, outpatient, home, or school settings.

It is apparent that this search included few studies that assessed the role of siblings and other peer-aged family members (i.e., cousins) in terms of the impact they have on the adolescent. Given that some chronically ill adolescents are unable to attend school (regularly, if at all), it would be interesting to better understand whether socialization among siblings impacts QoL. Siblings might offer friendship, distraction, or familiarity if they are able to visit with the adolescent during a treatment or inpatient stay.

In addition, few articles discussed the role of social media and social networks as impacting an adolescent's feelings of loneliness or isolation when unable to socialize in person (i.e., confined to the inpatient setting, unable to attend school, etc.) Perhaps as the presence of social media continues to be a main fixture of social society, studies will assess their impact and role in addressing social anxiety among adolescents.

Given the search terms used to identify articles, which focused on self-reported information from adolescents, the predictors related to the mental health status of the caregiver

are may not be representative of the breadth of predictors that are otherwise present in literature focused on parents of adolescents with chronic illnesses.

2.5 Tables and Figures

Figure 2.1 Flow Chart for Review of Articles in Initial Scopus Search

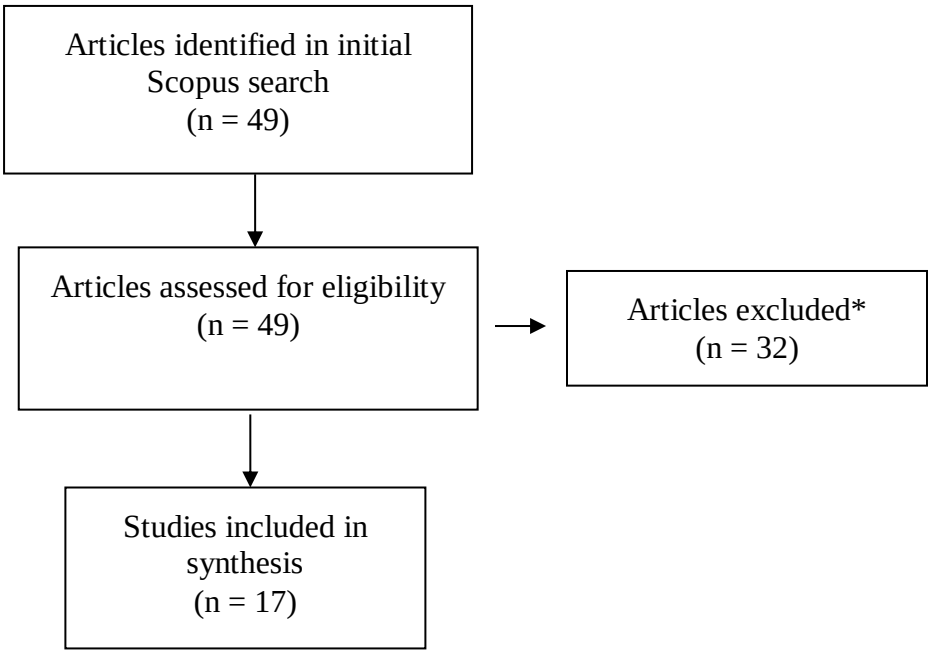

Table 2.1 Exclusion Reasons for Initial Scopus Search

***Exclusion Reasons**	**Number Excluded (n=32)**
Not assessing predictors of QoL or HRQoL	11
Not specific to adolescents (13-21)	11
Adolescent not self-reporting	8
Not a study (i.e., a commentary, scale development, tool validation, etc.)	2

Figure 2.2 Flow Chart for Review of All Referenced Articles

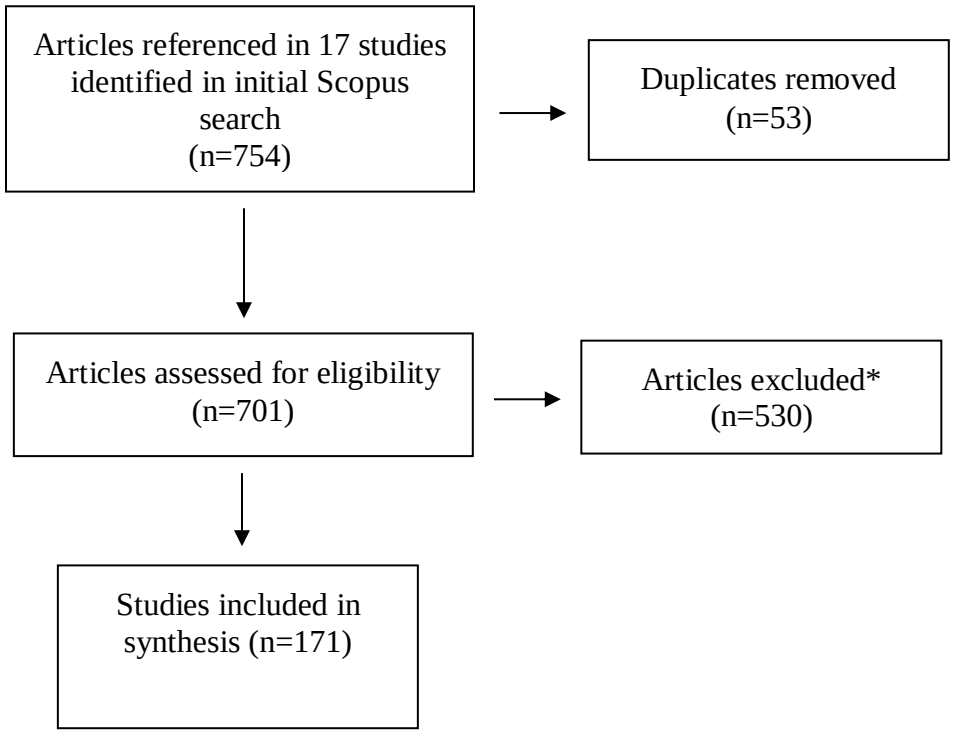

Table 2.2 Exclusion Reasons for Articles Referenced in Initial Scopus Search

***Exclusions Reasons**	**Number Excluded (n=530)**
Not assessing predictors of QoL or HRQoL	253
Not specific to adolescents (13-21)	70
Subjects do not have at least one chronic illness	15
Adolescent not self-reporting	12
Not focused on needs of adolescent (i.e., caregiver or sibling's needs or QoL)	4
Not a study with findings (i.e., commentary, scale development, tool validation, etc.)	156
Article not available in English	10
PhD thesis (unavailable)	4
Abstract only	4
Not held by libraries	2

Figure 2.3 Flow Chart for All Articles Included in Synthesis

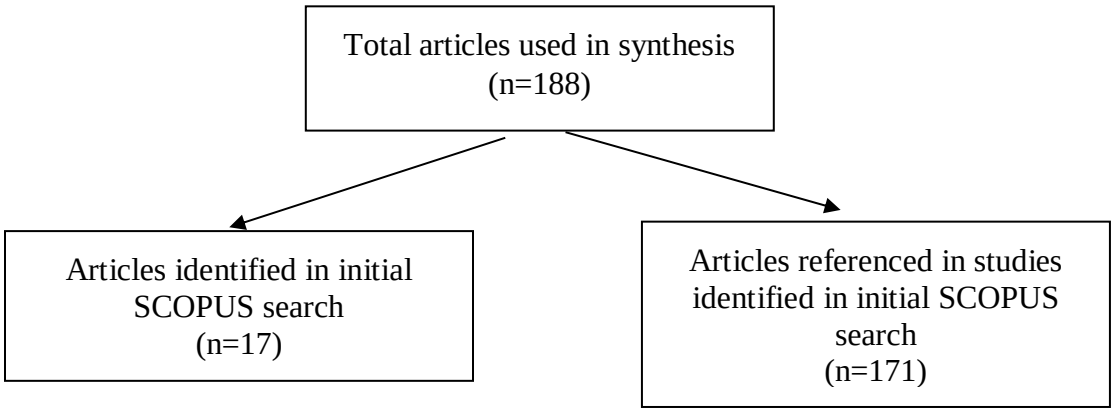

Table 2.3 Predictors of QoL or HRQoL among Chronically Ill Adolescents Summarized by Category

	Categories of Predictors of QoL or HRQoL among Chronically Ill Adolescents (Counts of articles reviewed citing predictors in the category)						
	Demographic Characteristics (23)	Use of Coping Strategies (40)	Psychosocial Factors (61)	Disease Control/ Management (81)	Mental Health Status of Adolescent (76)	Mental Health Status of Caregiver (5)	Physical Environment (1)
Predictors Cited	Age at diagnosis	Active coping	Social and emotional support available to teen	Presence of disease	Self-esteem	Parental psychopathology	Seasons (time of year)
	Age at treatment	Secondary control coping	Social and emotional support available to teen's family	Presence of comorbid diseases/symptoms	Mental health status, psychological well-being	Parental distress	
	Gender	Emotion-focused coping	Parental conflicts	Condition management, disease control	Depression	Parents' mental health/psychiatric health	
	Socioeconomic Status (SES)	Spiritual coping	Public perception of the disease	Which chronic condition they have	Ability to concentrate	Parent's/caregiver's mental health status	
	Height	Religious coping	Parental unemployment	Number of episodes or disease exacerbations	Anxiety	Parental alcohol problems	
	Birth weight	Wishful thinking	School participation	Method of disease management	Psychological factors		
	Type of insurance	Distance	Number of school days missed	Type of treatment regimen	Distress from illness uncertainty and intrusiveness		

	Family income	Praying	Achievement of educational and vocational milestones	Treatment satisfaction	Catastrophizing		
	Family structure	Acceptance	Dating anxiety	Extent of disease activity and/or disability	Psychological comorbidities		
	Maternal education	Self-focus	Use of social networks	Frequency of hospitalizations	Use of psychological therapies for pain management		
	Migration background						
		Cognitive behavioral therapy	Psychosocial education	Treatment adherence/non-adherence	Stress		
		Use of therapy for pain reduction	Number of missed work days	Psychosomatic symptoms	Perceived impact of disease		
		External locus of control	Loneliness	Medical transitions	Perceived impact of treatment regimen		
			Social functioning; ability to socialize	Ability to manage pain	Beliefs about illness		
			Anxiety about telling peers about illness	Pain, pain intensity	Psychological flexibility		
			School functioning	Pain frequency (recurring, chronic)	Cognitive and emotional issues		
			Interpersonal relationships associated with pain coping	Disease severity	Presence of personality disorder		

			Vulnerability	Disease self-management	Life satisfaction (present and future)		
			Family warmth and caring	Changes in health status	Resilience		
			Family support	Stiffness and fatigue	Body Image		
			Peer support/ rejection	Side-effects of treatment			
			Family psychosocial environment; family functioning	Number of medications			
			Ability to engage in day-to-day activities	Number of ED visits			
			Inclusion of friends in the treatment and disease management processes	Complications with disease			
			Sexual adaptation	Functional status			
			Development of romantic relationships				
			Social maturation				
			Identity formation				
			Development of autonomy/ independence				

			Psychosocial adjustment skills				
			Psychosocial distress				
			Having a personal confidant				
			Supportive services				
			Receipt of psychosocial guidance				
			Family adaptability				
			Counseling and education about disease				

Table 2.4 Predictors of QoL or HRQoL among Chronically Ill Adolescents

Authors	Title	Year	Predictors Cited (from article)	Categories Assigned
Oppenheimer S., Krispin O., Levy S., Ozeri M., Apter A.(42)	The impact of coping patterns and chronic health conditions on health-related quality of life among children and adolescents	2018	coping patterns (acceptance and distance); psychosocial interventions aimed at teaching and training coping patterns	use of coping strategies; psychosocial factors
Sawyer S.M., Drew S., Yeo M.S., Britto M.T.(91)	Adolescents with a chronic condition: challenges living, challenges treating	2007	condition management, social and emotional support, resilience	disease control/ management; psychosocial factors
Weisz J.R., McCabe M.A., Dennig M.D.(94)	Primary and Secondary Control Among Children Undergoing Medical Procedures: Adjustment as a Function of Coping Style	1994	secondary control coping (attempts to adjust oneself to objective conditions)	use of coping strategies
Hamlett K.W., Pellegrini D.S., Katz K.S.(61)	Childhood chronic illness as a family stressor	1992	social support available to the family	psychosocial factors
Meijer S.A., Sinnema G., Bijstra J.O., Mellenbergh G.J., Wolters W.H.G.(41)	Coping styles and locus of control as predictors for psychological adjustment of adolescents with a chronic illness	2002	social support; confrontation of issues	psychosocial support
Compas B.E., Desjardins L., Vannatta K., Young-Saleme T., Rodriguez E.M., Dunn M., Bemis H., Snyder S., Gerhardt C.A.(43)	Children and adolescents coping with cancer: Self - and parent reports of coping and anxiety/depression	2014	secondary control coping (efforts to adapt to source of stress; e.g., acceptance, cognitive reappraisal)	use of coping strategies
Dahlbeck D.T., Lightsey Jr. O.R.(44)	Generalized self-efficacy, coping, and self-esteem as predictors of psychological adjustment among children with disabilities or chronic illnesses	2008	self-esteem, emotional reaction coping	mental health status of adolescent

Petersen C., Schmidt S., Bullinger M., Quittan M., Schuhfried O., Nourafza R., Simeoni M.C., Orbicini D., Debensason D., Thyen U., Müller-Godeffroy E., Vidalis A., Tsanakas J., Hatziagorou E., Karagianni P., Koopman H., Baars R., Chaplin J.E., Power M., Atherton C., Hoare P.(95)	Coping with a chronic pediatric health condition and health-related quality of life	2006	coping strategies, especially emotional coping	use of coping strategies
Peeters Y., Boersma S.N., Koopman H.M.(96)	Predictors of quality of life: A quantitative investigation of the stress-coping model in children with asthma	2008	coping strategies - emotional reaction and avoidance	use of coping strategies
Petersen-Ewert C., Erhart M., Ravens-Sieberer U.(15)	Assessing health-related quality of life in European children and adolescents	2011	socio-economic status, gender, age, migration background, personality traits and coping with a chronic health condition, psychosocial risk factors (parental conflicts, alcohol or psychiatric problems of the parents, unemployment etc.), social support, social networks	Demographics; use of coping strategies; psychosocial factors; mental health status of caregiver
Quitmann J., Rohenkohl A., Specht A., Petersen-Ewert C., Schillmöller Z., Bullinger M.(45)	Coping Strategies of Children and Adolescents with Clinically Diagnosed Short Stature	2015	coping strategies - acceptance and distance	use of coping strategies
van Bussel A., Nieuwesteeg A., Janssen E., van Bakel H., van den Bergh B., Maas-van	Goal Disturbance and Coping in Children with Type I Diabetes Mellitus: Relationships with	2013	coping strategy of acceptance	use of coping strategies

Schaaijk N., Odink R., Rijk K., Hartman E.(97)	Health-Related Quality of Life and A1C			
Barthel D., Ravens-Sieberer U., Nolte S., Thyen U., Klein M., Walter O., Meyrose A.-K., Rose M., Otto C.(98)	Predictors of health-related quality of life in chronically ill children and adolescents over time	2018	disease control; mental health status of adolescent; mental health status of parent/caregiver	disease control/management; mental health status of adolescent; mental health status of caregiver
Naughton M.J., Ruggiero A.M., Lawrence J.M., Imperatore G., Klingensmith G.J., Waitzfelder B., McKeown R.E., Standiford D.A., Liese A.D., Loots B.(27)	Health-related quality of life of children and adolescents with type 1 or type 2 diabetes mellitus: SEARCH for Diabetes in Youth Study	2008	primary insurance source of Medicaid or another government-funded insurance, methods of disease self-management; comorbidities, and general disease management; sex; ED visits	demographics; disease control/management
Wagner V.M., Müller–Godeffroy E., Von Sengbusch S., Häger S., Thyen U.(19)	Age, metabolic control and type of insulin regime influences health-related quality of life in children and adolescents with type 1 diabetes mellitus	2005	Age, metabolic control and type of insulin regime	demographics; disease control/management
Lawrence J.M., Yi-Frazier J.P., Black M.H., Anderson A., Hood K., Imperatore G., Klingensmith G.J., Naughton M., Mayer-Davis E.J., Seid M.(14)	Demographic and clinical correlates of diabetes-related quality of life among youth with type 1 diabetes	2012	Age, sex, mode of diabetes management (insulin injection vs pump), having parents without a college degree, Medicaid/Medicare insurance, and having a comorbid medical condition, depression	demographics; disease control/management; mental health status of adolescent
Stahl-Pehe A., Straßburger K., Castillo K., Bächle C.,	Quality of life in intensively treated youths with early-onset	2014	disease control; treatment satisfaction	disease control/management

Holl R.W., Lange K., Rosenbauer J.(74)	type 1 diabetes: A population-based survey			
Giannakopoulos G., Dimitrakaki C., Pedeli X., Kolaitis G., Rotsika V., Ravens-Sieberer U., Tountas Y.(16)	Adolescents' wellbeing and functioning: Relationships with parents' subjective general physical and mental health	2009	Parental mental health status and physical health; Adolescents' gender, age, absence of chronic health care needs, high social support, and higher family income were positively associated with better HRQoL	mental health status of caregiver; demographics; psychosocial factors; disease control/management
Walker J., Winkelstein M., Land C., Lewis-Boyer L., Quartey R., Pham L., Butz A.(99)	Factors That Influence Quality of Life in Rural Children With Asthma and Their Parents	2008	school days missed; hospitalizations	psychosocial factors; disease control/management
Kim J., Chung H., Amtmann D., Salem R., Park R., Askew R.L.(100)	Symptoms and quality of life indicators among children with chronic medical conditions	2014	problems with disease symptoms	disease control/management
Svedberg P., Eriksson M., Boman E.(22)	Associations between scores of psychosomatic health symptoms and health-related quality of life in children and adolescents	2013	problems with sleep, depression, concentration, stomach aches, gender	mental health status of adolescent; demographics; disease control/management
Jonsson M., Bergström A., Egmar A.-C., Hedlin G., Lind T., Kull I.(101)	Asthma during adolescence impairs health-related quality of life	2016	smoking (exacerbation of chronic disease); gender	use of coping strategies; demographics
Barkmann C., Petermann F., Schlack R., Bullinger M., Schulte-Markwort M., Klasen F., Ravens-Sieberer U.(25)	Course of health-related quality of life: Results of the BELLA cohort study	2016	mental health problems and physical problems of the child, mental health problems of the parents, as well as age, gender,	mental health status of adolescent; mental health status of caregiver; demographics

			migrational background, and socioeconomic status.	
Otto C., Barthel D., Klasen F., Nolte S., Rose M., Meyrose A.-K., Klein M., Thyen U., Ravens-Sieberer U.(102)	Predictors of self-reported health-related quality of life according to the EQ-5D-Y in chronically ill children and adolescents with asthma, diabetes, and juvenile arthritis: longitudinal results	2018	number of health complaints; disease control; mental health status	disease control/management; mental health status of adolescent
Murillo M., Bel J., Pérez J., Corripio R., Carreras G., Herrero X., Mengibar J.-M., Rodriguez-Arjona D., Ravens-Sieberer U., Raat H., Rajmil L.(17)	Health-related quality of life (HRQOL) and its associated factors in children with Type 1 Diabetes Mellitus (T1DM)	2017	age, gender, family structure (single parent), adherence, mental health	demographics; psychosocial factors; disease control/management; mental health status of adolescent
Lundberg V., Lindh V., Eriksson C., Petersen S., Eurenius E.(70)	Health-related quality of life in girls and boys with juvenile idiopathic arthritis: Self- and parental reports in a cross-sectional study	2012	level of disease, level of disability	disease control/management
Kalyva E., Malakonaki E., Eiser C., Mamoulakis D.(18)	Health-related quality of life (HRQoL) of children with type 1 diabetes mellitus (T1DM): Self and parental perceptions	2011	age of disease onset, disease control, gender	demographics; disease control/management
Hassan K., Loar R., Anderson B.J., Heptulla R.A.(26)	The role of socioeconomic status, depression, quality of life, and glycemic control in type 1 diabetes mellitus	2006	disease control, SES, depression	disease control/management; demographics; mental health status of adolescent
Mullins A.J., Gamwell K.L., Sharkey C.M., Bakula D.M., Tackett A.P., Suorsa K.I.,	Illness uncertainty and illness intrusiveness as predictors of depressive and anxious	2017	psychological distress from illness uncertainty and intrusiveness	mental health status of adolescent

Chaney J.M., Mullins L.L.(103)	symptomology in college students with chronic illnesses			
Compas B.E., Jaser S.S., Dunn M.J., Rodriguez E.M.(104)	Coping with chronic illness in childhood and adolescence	2012	coping strategies	use of coping strategies
Jenkins R.A., Pargament K.I.(105)	Cognitive appraisals in cancer patients	1988	coping strategies	use of coping strategies
Wagner J.L., Chaney J.M., Hommel K.A., Page M.C., Mullins L.L., White M.M., Jarvis J.N.(106)	The influence of parental distress on child depressive symptoms in juvenile rheumatic diseases: The moderating effect of illness intrusiveness	2003	parental distress and child illness intrusiveness	mental health status of caregiver; mental health status of adolescent
Mullins L.L., Chaney J.M., Pace T.M., Hartman V.L.(107)	Illness uncertainty, attributional style, and psychological adjustment in older adolescents and young adults with asthma	1997	distress, disease uncertainty	mental health status of adolescent
Maslow G.R., Haydon A.A., Ford C.A., Halpern C.T.(108)	Young adult outcomes of children growing up with chronic illness: An analysis of the national longitudinal study of adolescent health	2011	achievement of educational and vocational milestones	psychosocial factors
Hommel K.A., Chaney J.M., Wagner J.L., White M.M., Hoff A.L., Mullins L.L.(109)	Anxiety and depression in older adolescents with long-standing asthma: The role of illness uncertainty	2003	illness uncertainty, psychosocial education, early identification and treatment of anxiety	mental health status of adolescent; psychosocial factors
Ferro M.A., Gorter J.W., Boyle M.H.(110)	Trajectories of depressive symptoms during the transition to young adulthood: The role of chronic illness	2015	depression	mental health status of adolescent

Hampel P., Rudolph H., Stachow R., Laß-Lentzsch A., Petermann F.(111)	Coping among children and adolescents with chronic illness	2005	coping strategies	use of coping strategies
Hoff A.L., Mullins L.L., Chaney J.M., Hartman V.L., Domek D.(88)	Illness uncertainty, perceived control, and psychological distress among adolescents with type 1 diabetes.	2002	disease uncertainty	mental health status of adolescent
Carpentier M.Y., Mullins L.L., Van Pelt J.C.(53)	Psychological, academic, and work functioning in college students with childhood-onset asthma	2007	anxiety, general psychological distress, missed school and work days, illness uncertainty and illness intrusiveness, psychological distress	mental health status of adolescent; psychosocial factors
Mullins L.L., Chaney J.M., Balderson B., Hommel K.A.(87)	The relationship of illness uncertainty, illness intrusiveness, and asthma severity to depression in young adults with long-standing asthma	2000	illness uncertainty	mental health status of adolescent
Fedele D.A., Mullins L.L., Eddington A.R., Ryan J.L., Junghans A.N., Hullmann S.E.(112)	Health-related quality of life in college students with and without childhood-onset asthma	2009	disease presence	disease control/management
Herts K.L., Wallis E., Maslow G.(77)	College freshmen with chronic illness: A comparison with healthy first-year students	2014	medical transition, loneliness	disease control/management; mental health status of adolescent

Fortier M.A., Batista M.L., Wahi A., Kain A., Strom S., Sender L.S.(113)	Illness uncertainty and quality of life in children with cancer	2013	illness uncertainty	mental health status of adolescent
Hundt N.E., Bensadon B.A., Stanley M.A., Petersen N.J., Kunik M.E., Kauth M.R., Cully J.A.(114)	Coping mediates the relationship between disease severity and illness intrusiveness among chronically ill patients	2015	illness intrusiveness, coping strategies	mental health status of adolescent; use of coping strategies
Ramsey R.R., Bonner M.S., Ryan J.L., Mullins L.L., Chaney J.M.(115)	A Prospective Examination of Attitudes Toward Illness and Depressive Symptoms in Youth with Juvenile Rheumatic Diseases	2013	depression	mental health status of adolescent
Molzon E.S., Hullmann S.E., Eddington A.R., Mullins L.L.(84)	Depression, Anxiety, and Health-Related Quality of Life in Adolescents and Young Adults With Allergies and Asthma	2011	depression, anxiety	mental health status of adolescent
Hullmann S.E., Molzon E.S., Eddington A.R., Mullins L.L.(89)	Dating Anxiety in Adolescents and Young Adults With Food Allergies: A Comparison to Healthy Peers	2012	dating anxiety, social functioning	mental health status of adolescent
Benore E., Pargament K., Pendleton S.(116)	An initial examination of religious coping in children with asthma	2008	religious coping	use of coping strategies
Cotton S., Grossoehme D., McGrady M.E.(34)	Religious coping and the use of prayer in children with sickle cell disease	2012	religious coping	use of coping strategies
Cotton S., Grossoehme D., Rosenthal S.L., McGrady M.E., Roberts Y.H., Hines J., Yi M.S., Tsevat J.(117)	Religious/spiritual coping in adolescents with sickle cell disease: A pilot study	2009	nothing studied predicted QoL or HRQoL	-
Cotton S., Kudel I., Roberts Y.H., Pallerla H., Tsevat J., Succop P., Yi M.S.(118)	Spiritual Well-Being and Mental Health Outcomes in Adolescents	2009	religious coping	use of coping strategies

	With or Without Inflammatory Bowel Disease			
Ezop S.J.(46)	Religious and spiritual coping in children with chronic illness	2002	religious coping; other forms of secular coping	use of coping strategies
Luberto C.M., Yi M.S., Tsevat J., Leonard A.C., Cotton S.(35)	Complementary and alternative medicine use and psychosocial outcomes among urban adolescents with asthma	2012	praying	use of coping strategies
Pendleton S.M., Cavalli K.S., Pargament K.I., Nasr S.Z.(47)	Religious/spiritual coping in childhood cystic fibrosis: a qualitative study.	2002	religious/spiritual coping	use of coping strategies
Reynolds N., Mrug S., Guion K.(119)	Spiritual coping and psychosocial adjustment of adolescents with chronic illness: The role of cognitive attributions, age, and disease group	2013	spiritual coping	use of coping strategies
Reynolds N., Mrug S., Hensler M., Guion K., Madan-Swain A.(120)	Spiritual coping and adjustment in adolescents with chronic illness: A 2-year prospective study	2014	spiritual coping	use of coping strategies
Warschburger P., Hänig J., Friedt M., Posovszky C., Schier M., Calvano C.(65)	Health-related quality of life in children with abdominal pain due to functional or organic gastrointestinal disorders	2014	pain; ability to manage pain; coping strategies; catastrophizing	disease control/management; mental health status of adolescent
Varni J.W., Limbers C.A., Burwinkle T.M.(121)	Impaired health-related quality of life in children and adolescents with chronic conditions: A comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the	2007	diagnosed chronic disease	disease control/management

	PedsQL™ 4.0 Generic Core Scales			
Di Lorenzo C., Colletti R.B., Lehmann H.P., Boyle J.T., Gerson W.T., Hyams J.S., Squires R.H., Walker L.S.(85)	Chronic abdominal pain in children: A clinical report of the American Academy of Pediatrics and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition	2005	distress, anxiety	mental health status of adolescent
Saps M., Seshadri R., Sztainberg M., Schaffer G., Marshall B.M., Di Lorenzo C.(122)	A Prospective School-based Study of Abdominal Pain and Other Common Somatic Complaints in Children	2009	presence of disease, school absenteeism, psychological co-morbidities	disease control/management; psychosocial factors; mental health status of adolescent
Reid G.J., Gilbert C.A., McGrath P.J.(36)	The pain coping questionnaire: Preliminary validation	1998	appraisals of pain controllability, self-rated coping effectiveness, emotional distress when in pain, and among high school students, pain thresholds and functional disability	disease control/management; use of coping strategies; mental health status of adolescent
Youssef N.N., Murphy T.G., Langseder A.L., Rosh J.R.(66)	Quality of life for children with functional abdominal pain: A comparison study of patients' and parents' perceptions	2006	presence of disease	disease control/management

Levy R.L., Langer S.L., Walker L.S., Romano J.M., Christie D.L., Youssef N., Dupen M.M., Feld A.D., Ballard S.A., Welsh E.M., Jeffery R.W., Young M., Coffey M.J., Whitehead W.E.(50)	Cognitive-behavioral therapy for children with functional abdominal pain and their parents decreases pain and other symptoms	2010	cognitive behavioral therapy to address distress	mental health status of adolescent
Varni J.W., Lane M.M., Burwinkle T.M., Fontaine E.N., Youssef N.N., Schwimmer J.B., Pardee P.E., Pohl J.F., Easley D.J.(123)	Health-related quality of life in pediatric patients with irritable bowel syndrome: A comparative analysis	2006	presence of disease, physical, Emotional, Social, and School Functioning	disease control/management; psychosocial factors; mental health status of adolescent
Van Der Zaag-Loonen H.J., Grootenhuis M.A., Last B.F., Derkx H.H.F.(124)	Coping strategies and quality of life of adolescents with inflammatory bowel disease	2004	coping styles	use of coping strategies
Warschburger P.(125)	The unhappy obese child	2005	psychosocial functioning	psychosocial factors
Walker L.S., Baber K.F., Garber J., Smith C.A.(37)	A typology of pain coping strategies in pediatric patients with chronic abdominal pain	2008	quality of patients' pain mastery efforts and interpersonal relationships associated with pain coping	disease control/management; psychosocial factors
Petersen S., Hägglöf B.L., Bergström E.I.(126)	Impaired health-related quality of life in children with recurrent pain	2009	recurrent pain	disease control/management
Otley A.R., Griffiths A.M., Hale S., Kugathasan S., Pfefferkorn M., Mezoff A., Rosh J., Tolia V., Markowitz J., Mack D., Oliva-Hemker M., Wyllie R., Rothbaum R.,	Health-related quality of life in the first year after a diagnosis of pediatric inflammatory bowel disease	2006	age, disease severity	demographics; disease control/management

Bousvaros A., Del Rosario J.F., Evans J., Blanchard W., Hyams J.(71)				
Merlijn V.P.B.M., Hunfeld J.A.M., Van Der Wouden J.C., Hazebroek-Kampschreur A.A.J.M., Passchier J., Koes B.W.(39)	Factors related to the quality of life in adolescents with chronic pain	2006	pain intensity, vulnerability, psychosocial factor such as emotion-focused avoidance coping strategies (ie, catastrophizing)	disease control/management; psychosocial factors; use of coping strategies
Groß M., Warschburger P.(51)	Evaluation of a cognitive-behavioral pain management program for children with chronic abdominal pain: A randomized controlled study	2013	use of cognitive behavioral therapy	mental health status of adolescent
Gold J.I., Yetwin A.K., Mahrer N.E., Carson M.C., Griffin A.T., Palmer S.N., Joseph M.H.(67)	Pediatric Chronic Pain and Health-Related Quality of Life	2009	levels of pain	disease control/management
Huguet A., Eccleston C., Miró J., Gauntlett-Gilbert J.(127)	Young people making sense of pain: Cognitive appraisal, function, and pain in 8-16 year old children	2009	positive expectations about ability, the responsibility to exert control over the pain, the belief that medication and doctors will help to control the pain	psychosocial factors; disease control/management
Du Y., Knopf H., Zhuang W., Ellert U.(128)	Pain perceived in a national community sample of German children and adolescents	2011	SES	demographics

Jarrett M., Heitkemper M., Czyzewski D.I., Shulman R.(129)	Recurrent abdominal pain in children: forerunner to adult irritable bowel syndrome?	2003	Physiological mechanisms not easily identifiable as an organic cause	mental health status of adolescent
Hill R.J., Lewindon P.J., Muir R., Grangé I., Connor F.L., Ee L., Withers G.D., Cleghorn G.J., Davies P.S.W.(130)	Quality of life in children with crohn disease	2010	how long they've had the disease	demographics
Hainsworth K.R., Davies W.H., Khan K.A., Weisman S.J.(131)	Co-occurring chronic pain and obesity in children and adolescents: The impact on health-related quality of life	2009	Co-occurring chronic pain and obesity	disease control/management
Greenley R.N., Kunz J.H., Schurman J.V., Swanson E.(132)	Abdominal pain and health related quality of life in pediatric inflammatory bowel disease	2013	presence of pain	disease control/management
Gross M., Warschburger P.(133)	Chronic abdominal pain: Psychosocial strain and treatment-associated changes in coping	2013	stress reduction, improved psychosocial functioning	mental health status of adolescent; psychosocial factors
Hermann C., Hohmeister J.(134)	Pain-related catastrophizing in children and adolescents: Theoretical concept, measurement, and clinical relevance	2012	catastrophizing	mental health status of adolescent
Guo J., Whittemore R., Grey M., Wang J., Zhou Z.-G., He G.-P.(135)	Diabetes self-management, depressive symptoms, quality of life and metabolic control in youth with type 1 diabetes in China	2013	disease self-management; depressive symptoms	disease control/management; mental health status of adolescent

Kovacs M., Goldston D., Obrosky D.S., Bonar L.K.(136)	Psychiatric disorders in youths with IDDM: Rates and risk factors	1997	psychological status	mental health status of adolescent
Grey M., Boland E.A., Yu C., Sullivan-Bolyai S., Tamborlane W.V.(137)	Personal and family factors associated with quality of life in adolescents with diabetes	1998	family warmth and caring, intensity of disease, satisfaction with disease management	psychosocial factors; disease control/management
Grey M., Boland E.A., Davidson M., Yu C., Sullivan-Bolyai S., Tamborlane W.V.(138)	Short-term effects of coping skills training as adjunct to intensive therapy in adolescents	1998	receipt of coping skills training class	use of coping strategies
Skinner T.C., John M., Hampson S.E.(62)	Social support and personal models of diabetes as predictors of self- care and well-being: A longitudinal study of adolescents with diabetes	2000	Perceived impact of diabetes, supportive family and friends	disease control/management; psychosocial factors
McKellar J.D., Humphreys K., Piette J.D.(139)	Depression Increases Diabetes Symptoms by Complicating Patients' Self-Care Adherence	2004	depression	mental health status of adolescent
Grey M., Davidson M., Boland E.A., Tamborlane W.V.(40)	Clinical and psychosocial factors associated with achievement of treatment goals in adolescents with diabetes mellitus	2001	depression, participation in coping skills training class	mental health status of adolescent; use of coping strategies
Chas Skinner T., Hampson S.E.(140)	Personal Models of Diabetes in Relation to Self-Care, Well-Being and Glycemic Control: A Prospective study in adolescence	2001	Perceived impact of diabetes, perceived effectiveness in treatment regimen	mental health status of adolescent

Stewart S.M., Rao U., Emslie G.J., Klein D., White P.C.(141)	Depressive symptoms predict hospitalization for adolescents with type 1 diabetes mellitus	2005	depression	mental health status of adolescent
Nardi L., Zucchini S., D'alberton F., Salardi S., Maltoni G., Bisacchi N., Elleri D., Cicognani A.(142)	Quality of life, psychological adjustment and metabolic control in youths with type 1 diabetes: A study with self- and parent-report questionnaires	2008	control and management of disease	disease control/management
Whittemore R., Kanner S., Singleton S., Hamrin V., Chiu J., Grey M.(143)	Correlates of depressive symptoms in adolescents with type 1 diabetes	2002	depression, depressive symptoms	mental health status of adolescent
Faulkner M.S., Chang L.-I.(144)	Family Influence on Self-Care, Quality of Life, and Metabolic Control in School-Age Children and Adolescents with Type 1 Diabetes	2007	warm and caring family behaviors	psychosocial factors
Law G.U., Kelly T.P., Huey D., Summerbell C.(86)	Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role?	2002	illness beliefs (my illness makes me different than other people, etc.)	mental health status of adolescent
Ausili E., Tabacco F., Focarelli B., Padua L., Crea F., Caliandro P., Pazzaglia C., Marietti G., Rendeli C.(145)	Multidimensional study on quality of life in children with type 1 diabetes	2007	age, disease control, disease management	demographics, disease control/management
Meltzer E.O., Nathan R.A., Selner J.C., Storms W.(146)	Quality of life and rhinitic symptoms: Results of a nationwide survey with the SF-36 and RQLQ questionnaires	1997	changes in health status	disease control/management

Marklund B., Ahlstedt S., Nordström G.(147)	Health-related quality of life among adolescents with allergy-like conditions - With emphasis on food hypersensitivity	2004	presence of allergy-like conditions and/or sensitivities	disease control/management
Calsbeek H., Rijken M., Bekkers M.J.T.M., Dekker J., Van Berge Henegouwen G.P.(148)	School and leisure activities in adolescents and young adults with chronic digestive disorders: Impact of burden of disease	2006	disease burden characteristics, especially depression	mental health status of adolescent
Ellis A.K., Day J.H., Lundie M.J.(149)	Impact on quality of life during an allergen challenge research trial	1999	symptoms of illness	disease control/management
Eddington A.R., Mullins L.L., Fedele D.A., Ryan J.L., Junghans A.N.(150)	Dating relationships in college students with childhood-onset asthma	2010	dating anxiety because of illness	psychosocial factors
Feinstein A.B., Forman E.M., Masuda A., Cohen L.L., Herbert J.D., Nandini Moorthy L., Goldsmith D.P.(92)	Pain intensity, psychological inflexibility, and acceptance of pain as predictors of functioning in adolescents with Juvenile idiopathic arthritis: A preliminary investigation	2011	psychological flexibility (acceptance)	mental health status of adolescent
Wicksell R.K., Melin L., Lekander M., Olsson G.L.(38)	Evaluating the effectiveness of exposure and acceptance strategies to improve functioning and quality of life in longstanding pediatric pain - A randomized controlled trial	2009	Acceptance and Commitment Therapy for pain	use of coping strategies
Gauntlett-Gilbert J., Eccleston C.(151)	Disability in adolescents with chronic pain: Patterns and predictors across different domains of functioning	2007	pain intensity, depression	disease control/management; mental health status of adolescent

Logan D.E., Scharff L.(152)	Relationships between family and parent characteristics and functional abilities in children with recurrent pain syndromes: An investigation of moderating effects on the pathway from pain to disability	2005	recurrent pain, family characteristics	disease control/management; demographics
Schanberg L.E., Anthony K.K., Gil K.M., Maurin E.C.(54)	Daily pain and symptoms in children with polyarticular arthritis	2003	pain, stiffness, fatigue, participation in school and social activities	disease control/management; psychosocial factors
Wicksell R.K., Melin L., Olsson G.L.(153)	Exposure and acceptance in the rehabilitation of adolescents with idiopathic chronic pain - A pilot study	2007	exposure and acceptance for chronic and debilitating pain	use of coping strategies; disease control/management
Billings A.G., Moos R.H., Miller 3rd. J.J., Gottlieb J.E.(56)	Psychosocial adaptation in juvenile rheumatic disease: a controlled evaluation.	1987	school participation, participation in social activities	psychosocial factors
Schanberg L.E., Lefebvre J.C., Keefe F.J., Kredich D.W., Gil K.M.(154)	Pain coping and the pain experience in children with juvenile chronic arthritis	1997	pain coping skills	use of coping strategies
Thompson K.L., Varni J.W., Hanson V.(155)	Comprehensive assessment of pain in juvenile rheumatoid arthritis: An empirical model	1987	family environment, and psychological factors	psychosocial factors; mental health status of adolescent
Schanberg L.E., Gil K.M., Anthony K.K., Yow E., Rochon J.(59)	Pain, stiffness, and fatigue in juvenile polyarticular arthritis: Contemporaneous stressful events and mood as predictors	2005	Stress, mood, participation in school and social activities	mental health status of adolescent; psychosocial factors
Sandstrom M.J., Schanberg L.E.(156)	Brief Report: Peer Rejection, Social Behavior, and Psychological Adjustment in Children with Juvenile Rheumatic Disease	2004	pain, peer rejection, depression	disease control/management; psychosocial factors; mental health status of adolescent

Varni J.W., Wilcox K.T., Hanson V., Brik R.(55)	Chronic musculoskeletal pain and functional status in juvenile rheumatoid arthritis: an empirical model	1988	Child psychological adjustment, family psychosocial environment, chronic musculoskeletal pain, and disease activity	mental health status of adolescent; psychosocial factors; disease management and control
Wicksell R.K., Dahl J., Magnusson B., Olsson G.L.(157)	Using acceptance and commitment therapy in the rehabilitation of an adolescent female with chronic pain: A case example	2005	chronic pain	disease control/management
McCracken L.M., Gauntlett-Gilbert J., Eccleston C.(158)	Acceptance of pain in adolescents with chronic pain: Validation of an adapted assessment instrument and preliminary correlation analyses	2010	acceptance, disability, psychological distress, and developmental and family functioning	mental health status of adolescent; psychosocial factors; disease management and control
April K.T., Feldman D.E., Platt R.W., Duffy C.M.(159)	Comparison between children with Juvenile Idiopathic Arthritis (JIA) and their parents concerning perceived quality of life	2006	disease severity	disease control/management
Sawyer M.G., Carbone J.A., Whitham J.N., Roberton D.M., Taplin J.E., Varni J.W., Baghurst P.A.(160)	The relationship between health-related quality of life, pain, and coping strategies in juvenile arthritis - A one year prospective study	2005	pain	disease control/management
Margetić B., Aukst-Margetić B., Bilić E., Jelušić M., Bukovac L.T.(161)	Depression, anxiety and pain in children with juvenile idiopathic arthritis (JIA)	2005	pain, depression	disease control/management; mental health status of adolescent

Gong G.W.K., Young N.L., Dempster H., Porepa M., Feldman B.M.(162)	The quality of my life questionnaire: The minimal clinically important difference for pediatric rheumatology patients	2007	pain, disease severity	disease control/management
Juniper E.F.(163)	Quality of life in adults and children with asthma and rhinitis	1997	symptoms of illness, ability to engage in day-to-day activities, ability to socialize	disease control/management; psychosocial factors
La Greca A.M., Bearman K.J., Moore H.(164)	Peer relations of youth with pediatric conditions and health risks: Promoting social support and healthy lifestyles	2002	peer support, including friends in treatment and disease management processes	psychosocial factors
Thoren C.T., Petermann F.(165)	Reviewing asthma and anxiety	2000	anxiety	mental health status of adolescent
Gillaspy S.R., Hoff A.L., Mullins L.L., Van Pelt J.C., Chaney J.M.(166)	Psychological distress in high-risk youth with asthma	2002	anxiety, depression, psychological stress	mental health status of adolescent
Anderson B.J., Wolf F.M.(167)	Chronic Physical Illness and Sexual Behavior. Psychological Issues	1986	sexual adaptation	psychosocial factors
Nishimura K., Hajiro T., Oga T., Tsukino M., Ikeda A.(168)	Health Related Quality of Life in Stable Asthma: What Are Remaining Quality of Life Problems in Patients with Well-Controlled Asthma?	2004	psychological well-being	mental health status of adolescent
Thompson A.L., Marsland A.L., Marshal M.P., Tersak J.M.(169)	Romantic relationship of emerging adult survivors of childhood cancer	2009	identity development, such as romantic relationships	psychosocial factors
Kokkonen J.(170)	The social effects in adult life of chronic physical illness since childhood	1995	social maturation	psychosocial factors

Van Pelt J.C., Mullins L.L., Carpentier M.Y., Wolfe-Christensen C.(48)	Brief report: Illness uncertainty and dispositional self-focus in adolescents and young adults with childhood-onset asthma	2006	increased self-focus, psychological distress	use of coping strategies; mental health status of adolescent
Taylor R.M., Franck L.S., Gibson F., Donaldson N., Dhawan A.(78)	Study of the factors affecting health-related quality of life in adolescents after liver transplantation	2009	side effects of immunosuppression after transplant (ie: headaches); development of a second chronic illness as a result of immunosuppression; psychosocial factors; self-esteem	disease control/management; psychosocial factors; mental health status of adolescent
Powers S.W., Patton S.R., Hommel K.A., Hershey A.D.(171)	Quality of life in childhood migraines: clinical impact and comparison to other chronic illnesses.	2003	impairments in school and emotional functioning	psychosocial factors
Devinsky O., Westbrook L., Cramer J., Glassman M., Perrine K., Camfield C.(172)	Risk factors for poor health-related quality of life in adolescents with epilepsy	1999	age, disease severity	demographics; disease control/management
Gibson P.G., Henry R.L., Vimpani G.V., Halliday J.(68)	Asthma knowledge, attitudes, and quality of life in adolescents	1995	presence of disease	disease control/management
Fredericks E.M., Lopez M.J., Magee J.C., Shieck V., Opipari-Arrigan L.(73)	Psychological functioning, nonadherence and health outcomes after pediatric liver transplantation	2007	nonadherence to treatment regimen	disease control/management
McEwan M.J., Espie C.A., Metcalfe J., Brodie M.J., Wilson M.T.(173)	Quality of life and psychosocial development in adolescents with epilepsy: A qualitative investigation using focus group methods	2004	identity formation, peer acceptance, developing autonomy	psychosocial factors

Fredericks E.M., Magee J.C., Opipari-Arrigan L., Shieck V., Well A., Lopez M.J.(72)	Adherence and health-related quality of life in adolescent liver transplant recipients	2008	nonadherence to treatment regimen	disease control/management
Atkin K., Ahmad W.I.U(174)	Living a 'normal' life: Young people coping with thalassaemia major or sickle cell disorder	2001	coping strategies	use of coping strategies
Taylor R.M., Gibson F., Franck L.S.(29)	A concept analysis of health-related quality of life in young people with chronic illness	2008	peer support, family support	psychosocial factors
Taylor R.M., Franck L.S., Gibson F., Dhawan A.(175)	A critical review of the health-related quality of life of children and adolescents after liver transplantation	2005	having a medical procedure	disease control/management
Miller V., Palermo T.M., Grewe S.D.(176)	Quality of life in pediatric epilepsy: Demographic and disease-related predictors and comparison with healthy controls	2003	comorbid neurological impairments, number of medications	disease control/management
Sundaram S.S., Landgraf J.M., Neighbors K., Cohn R.A., Alonso E.M.(79)	Adolescent health-related quality of life following liver and kidney transplantation	2007	self-esteem, mental health, pain	mental health status of adolescent; disease control/management
Vila G., Hayder R., Bertrand C., Falissard B., De Blic J., Mouren-Simeoni M.-C., Scheinmann P.(177)	Psychopathology and quality of life for adolescents with asthma and their parents	2003	duration of illness, its pretreatment severity, hospitalizations in the past year, psychological variables	disease control/management; mental health status of adolescent
Okelo S.O., Wu A.W., Krishnan J.A., Rand C.S., Skinner E.A., Diette G.B.(57)	Emotional quality-of-life and outcomes in adolescents with asthma	2004	feeling depressed, ED visits, missing school	mental health status of adolescent; disease control/management; psychosocial factors
Graue M., Wentzel-Larsen T., Hanestad B.R., Søvik O.(30)	Health-related quality of life and metabolic control in adolescents with diabetes: The role of	2005	family support	psychosocial factors

	parental care, control, and involvement			
Adebäck P., Nemeth A., Fischler B.(93)	Cognitive and emotional outcome after pediatric liver transplantation	2003	cognitive and emotional issues	mental health status of adolescent
Erickson S., Munzenberger P., Plante M., Kirking D., Hurwitz M., Vanuya R.(24)	Influence of sociodemographics on the health-related quality of life of pediatric patients with asthma and their caregivers	2002	household income	demographics
Frare M., Axia G., Battistella P.A.(31)	Quality of life, coping strategies, and family routines in children with headache	2002	pain, family support	disease control/management; psychosocial factors
Törnqvist J., Van Broeck N., Finkenauer C., Rosati R., Schwering K.-L., Hayez J.-Y., Janssen M., Otte J.-B.(178)	Long-term psychosocial adjustment following pediatric liver transplantation	1999	psychosocial adjustment skills	psychosocial factors
Chen H., Cohen P., Kasen S., Johnson J.G., Berenson K., Gordon K.(179)	Impact of adolescent mental disorders and physical illnesses on quality of life 17 years later	2006	presence of personality disorder	mental health status of adolescent
Kahana S.Y., Frazier T.W., Drotar D.(180)	Preliminary quantitative investigation of predictors of treatment non-adherence in pediatric transplantation: A brief report	2008	nonadherence to treatment regimen, comorbid psychiatric conditions	disease management/control; mental health status of adolescent
Key J.D., Brown R.T., Marsh L.D., Spratt E.G., Recknor J.C.(181)	Depressive symptoms in adolescents with a chronic illness	2001	disease severity, depression	disease control/management; mental health status of adolescent

Barrera M., Wayland L.-A., D'Agostino N.M., Gibson J., Weksberg R., Malkin D.(21)	Developmental differences in psychological adjustment and health-related quality of life in pediatric cancer patients	2003	age	demographics
Zamberlan K.E.(82)	Quality of life in school-age children following liver transplantation.	1992	psychosocial adjustment, changes in physical appearance and physical functioning; emotions, fears, or concerns about rejection and future outcome of the liver transplant(s); and children's satisfaction with present and future life, and thoughts about self	psychosocial factors, mental health status of adolescent
Langeveld J.H., Koot H.M., Passchier J.(182)	Do experienced stress and trait negative affectivity moderate the relationship between headache and quality of life in adolescents?	1999	headache; functional status, satisfaction with life in general, and satisfaction with health	disease control/management; mental health status of adolescent
Faugli A., Bjørnland K., Emblem R., Nøvik T.S., Diseth T.H.(23)	Mental health and psychosocial functioning in adolescents with esophageal atresia	2009	height, birth weight, well-being, dissociative symptoms, family strain	demographics; mental health status of adolescent; psychosocial factors
Diseth T.H., Bjordal R., Schultz A., Stange M., Emblem R.(183)	Somatic function, mental health and psychosocial functioning in 22 adolescents with bladder exstrophy and epispadias	1998	management of disease symptoms	disease control/management
Geist R., Grdisa V., Otley A.(184)	Psychosocial issues in the child with chronic conditions	2003	psychosocial distress	mental health status of adolescent
Vitulano L.A.(58)	Psychosocial issues for children and adolescents with chronic illness: Self-esteem, school	2003	involvement in activities with peers	psychosocial factors

	functioning and sports participation			
Stuber M.L., Shemesh E.(32)	Post-traumatic Stress Response to Life-Threatening Illnesses in Children and Their Parents	2006	role of family and caregivers	psychosocial factors
Piazza-Waggoner C., Adams C.D., Cottrell L., Taylor B.K., Wilson N.W., Hogan M.B.(33)	Child and caregiver psychosocial functioning in pediatric immunodeficiency disorders	2006	psychosocial functioning	psychosocial factors
Erling A.(185)	Why do some children of short stature develop psychologically well while others have problems?	2004	psychosocial stress	psychosocial factors
Landolt M.A., Vollrath M., Niggli F.K., Gnehm H.E., Sennhauser F.H.(69)	Health-related quality of life in children with newly diagnosed cancer: A one year follow-up study	2006	Intensity of treatment, presence of medical complications, parental psychopathology	disease control/management; mental health status of caregiver
Sawyer M.G., Reynolds K.E., Couper J.J., French D.J., Kennedy D., Martin J., Staugas R., Ziaian T., Baghurst P.A.(186)	Health-related quality of life of children and adolescents with chronic illness - A two year prospective study	2004	adjustment to managing disease with physical and family activities	psychosocial factors; disease control/management
Sawyer M.G., Spurrier N., Whaites L., Kennedy D., Martin A.J., Baghurst P.(160)	The relationship between asthma severity, family functioning and the health-related quality of life of children with asthma	2000	presence of disease; mental health; social functioning	disease control/management; mental health status of adolescent; psychosocial factors
Hesselink A.E., Penninx B.W.J.H., Schlösser M.A.G., Wijnhoven H.A.H., Van Der Windt D.A.W.M.,	The role of coping resources and coping style in quality of life of patients with asthma or COPD	2004	psychosocial coping resources; coping style	use of coping strategies; psychosocial factors

Kriegsman D.M.W., Van Eijk J.Th.M.(187)				
García-Marcos L., Carvajal Urueña I., Escribano Montaner A., Fernández Benítez M., García De La Rubia S., Tauler Toro E., Pérez Fernández V., Barcina Sánchez C.(90)	Seasons and other factors affecting the quality of life of asthmatic children	2007	seasons (time of year) for asthma patients	environmental
Shaligram D., Girimaji S.C., Chaturvedi S.K.(83)	Psychological problems and quality of life in children with thalassemia	2007	psychological problems, especially depression; side effects of illness	mental health status of adolescent; disease control/management
Mikelli A., Tsiantis J.(188)	Brief report: Depressive symptoms and quality of life in adolescents with b-thalassaemia	2004	depressive symptoms, coping strategies	mental health status and adolescent; use of coping strategies
Pradhan P.V., Shah H., Rao P., Ashturkar D., Ghaisas P.(80)	Psychopathology and self-esteem in chronic illness	2003	self-esteem	mental health status of adolescent
Woo R., Giardina P.J.V., Hilgartner M.W.(189)	A Psychosocial Needs Assessment of Patients with Homozygous β-Thalassemia	1985	counseling and education about disease, personal confidant, coping skills, supportive services, independence and autonomy	psychosocial factors; use of coping strategies
Patel A.B., Pathan H.G.(190)	Quality of life in children with sickle cell hemoglobinopathy	2005	presence of disease	disease control/management
Bucuvalas J.C., Britto M., Krug S., Ryckman F.C., Atherton H., Alonso M.P.,	Health-related quality of life in pediatric liver transplant recipients: A single-center study	2003	age at transplantation, maternal education	demographics

Ballistreri W.F., Kotagal U.(20)				
Britto M.T., Kotagal U.R., Atherton H.D., Wilmott R.W., Hornung R.W., Tsevat J.(191)	Impact of recent pulmonary exacerbations on quality of life in patients with cystic fibrosis	2002	exacerbation of disease (episode)	disease control/management
Midgley D.E., Bradlee T.A., Donohoe C., Kent K.P., Alonso E.M.(192)	Health-related quality of life in long-term survivors of pediatric liver transplantation	2000	presence of disease	disease control/management
Apajasalo M., Rautonen J., Sintonen H., Holmberg C.(75)	Health-related quality of life after organ transplantation in childhood	1997	issues with mobility, usual activities, and school and hobbies, eating, elimination, friends and ability to concentrate	disease control/management; psychosocial factors; mental health status of adolescent
Asonuma K., Inomata Y., Uemoto S., Egawa H., Kiuchi T., Okajima H., James Shapiro A.M., Tanaka K.(193)	Growth and quality of life after living-related liver transplantation in children	1998	ability to do normal daily activities	disease control/management
Sokal E.M.(194)	Quality of life after orthotopic liver transplantation in children. An overview of physical, psychological and social outcome	1995	fewer medications, fewer inpatient visits, school attendance, normal interactions with peers, more independent	disease control/management; psychosocial factors
Anyanwu I., Anyanwu E.(195)	Assessment of the psychosocial impacts of sickle cell disease on adolescents and how parents and relatives cope with pain in the family	2001	whether or not received psychosocial guidance	psychosocial factors

Brown R.T., Kaslow N.J., Doepke K., Buchanan I., Eckman J., Baldwin K., Goonan B.(196)	Psychosocial and Family Functioning in Children with Sickle Cell Syndrome and Their Mothers	1993	adaptive coping strategies	use of coping strategies
Hariman L.M.F., Griffith E.R., Hurtig A.L., Keehn M.T.(197)	Functional outcomes of children with sickle-cell disease affected by stroke	1991	psychosocial deficits	psychosocial factors
Noll R.B., Ris M.D., Davies W.H., Bukowski W.M., Koontz K.(198)	Social interactions between children with cancer or sickle cell disease and their peers: Teacher ratings	1992	resilience	mental health status of adolescent
Shapiro B.S., Cohen D.E., Howe C.J.(199)	Patient-controlled analgesia for sickle-cell-related pain	1993	ability to control pain medicine dosage and usage	disease control/management
Sharpe J.N., Brown R.T., Thompson N.J., Eckman J.(200)	Predictors of Coping with Pain in Mothers and Their Children with Sickle Cell Syndrome	1994	family adaptability, coping skills	psychosocial factors; use of coping strategies
Adedoyin M.A.(64)	Psychosocial effects of sickle cell disease among adolescents.	1992	A sense of shame in public, inability to play games of their choice, fear of dying young, fear of not achieving their goals in life	psychosocial factors; mental health status of adolescent
Bauld C., Anderson V., Arnold J.(201)	Psychosocial aspects of adolescent cancer survival	1998	coping strategies, age, gender	use of coping strategies; demographics
Zeltzer L., Kellerman J., Ellenberg L., Dash J., Rigler D.(81)	Psychologic effects of illness in adolescence. II. Impact of illness in adolescents-crucial issues and coping styles	1980	disruption of body image, school disruption, restriction of freedom	mental health status of adolescent; psychosocial factors
Greenberg H.S., Kazak A.E., Meadows A.T.(202)	Psychologic functioning in 8- to 16-year-old cancer survivors and their parents	1989	self-concept, depressive symptoms, external locus of control	mental health status of adolescent; use of coping strategies

Wasserman A.L., Thompson E.I., Wilimas J.A., Fairclough D.L.(203)	The Psychological Status of Survivors of Childhood/Adolescent Hodgkin's Disease	1987	side effects of treatment	disease control/management
Zeltzer L.K.(204)	Cancer in adolescents and young adults psychosocial aspects. Long-term survivors.	1993	side effects of treatment	disease control/management
Chang P.-N., Nesbit M.E.(205)	Personality characteristics and psychosocial adjustment of long-term survivors of childhood cancer	1988	psychosocial factors	psychosocial factors

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CHAPTER 3. INPATIENT STRATEGIES OFFERED BY CHILDREN'S HOSPITALS IN THE SOUTHEAST UNITED STATES TARGETING QUALITY OF LIFE AND HEALTH-RELATED QUALITY OF LIFE FOR CHRONICLLY ILL ADOLESCENTS

ABSTRACT

Background: The first part of this chapter summarizes inpatient programs available to adolescents at 11 children's hospitals in the southeast United States. The chapter focuses on three of the seven categories of predictors of QoL identified in Chapter 2. These three categories are most actionable in terms of hospital interventions. They include the use of coping strategies, psychosocial factors, and the mental health status of the adolescent. In the second part of the chapter, one particular program is featured as a case study. Streetlight, at the University of Florida Shands Children's Hospital, is a 1:1 peer support program that seeks to enhance QoL and/or HRQoL for chronically ill adolescents. This section summarizes feedback and insight from chronically ill adolescents who have participated in Streetlight.

Methods: Eleven children's hospitals in the southeast U.S. were selected given 1) the high prevalence of chronic conditions in the mid-South compared to other regions in the U.S., and 2) their ranking according to U.S. News and World report as offering "advanced palliative care" services to children and adolescents. The targeted review of their program offerings was first conducted according to publicly available information on the hospitals' websites, and then confirmed with hospital administration via nine completed phone calls. The case study featuring Streetlight utilized de-identified transcripts of patient interviews. Utilizing thematic analysis, patients' insights and comments about the program were summarized and discussed in the context of three categories of predictors of QoL and HRQoL identified in Chapter 2.

Results: The review of children's hospital websites found that all 11 hospitals offer chronically ill adolescents interventions that address the use of coping skills, psychosocial factors, and their mental health status. Specifically, each hospital offers some form of child life therapy, pet therapy, art therapy, music therapy, the opportunity to interact with general hospital volunteers, and pastoral care/spiritual support services. Ten hospitals offer a teen-specific room or area, in which teens can take a break from the medical setting and interact with other adolescents. Eight hospitals offer a hospital-based school program. Five of the 11 hospitals offer at least one disease-specific integrated psychosocial clinical care team to develop and manage the patient's plan of care. Five hospitals offer adolescents the opportunity to engage with an on-site media center or radio station run by the hospital. Three hospitals offer 1:1 peer support programs, in which volunteers in their late teens and early twenties partner with patients during their inpatient stay. Three hospitals offer formal family-to-family mentorship programs, in which families of adolescents with similar diagnoses provide mutual support.

The case study focused on patients' perspectives of a 1:1 peer support program, Streetlight, at UF Health Shands, and the impact of this program on coping skills, psychosocial factors, and mental health. While 1:1 peer support programs are also offered to pediatric patients at Wolfson's Children's and UNC Children's, the Streetlight program at UF Health Shands is specific to adolescents. Interviewees described the ways in which Streetlight helps them cope by offering companionship, and easing their burdens, for example. In addition, study participants describe Streetlight's role in addressing psychosocial factors such as helping them to connect with peers and serving as a sort of family for them in the inpatient setting. Finally, they offer comments about Streetlight that address aspects of enhancing their mental health status. These

include Streetlight helping to infuse joy and inspiration into their lives and serving as a resource for them when they are depressed or feeling isolated.

Conclusions: This sample of 11 children's hospitals in the southeast U.S. offers a wide variety of supportive programs to chronically ill adolescents in the inpatient setting. These programs address predictors of QoL identified in Chapter 2 that are centered around the use of coping skills, psychosocial factors, and the mental health status of the adolescent. While all hospitals offer a standard suite of programs (Child Life therapy, pet therapy, art therapy, music therapy, general hospital volunteers, pastoral care/spiritual support), three hospitals in this sample additionally offer 1:1 peer support programs. These include Emerging Pediatric Professionals at Wolfson's Children's, Streetlight at UF Health Shands Children's Hospital, and Carolina Pediatric Attention Love and Support at UNC Children's Hospital. These institutions also provide opportunities for undergraduate students at nearby universities to serve as volunteers. They spend time at the bedside, getting to know the patients, playing games, and offering companionship. They often establish relationships with patients, visiting them during their inpatient stays. In some cases, they also get to know the patients' family members.

The Streetlight program at UF Health Shands is specifically tailored to adolescents, regardless of their chronic illness. Interviews with patients who have participated in Streetlight reveal the specific ways in which the program enhances QoL. Further study is needed to understand adolescents' perspectives on whether other inpatient programs similarly enhance QoL by addressing coping skills, psychosocial factors, and their mental health status.

Keywords: adolescent, teenager, psychosocial, well-being, chronic illness, chronically ill, palliative care

Running Title: Inpatient Strategies Targeting QoL for Chronically Ill Adolescents

3.1 Background

Healthcare providers, friends, and family members, play an important role in helping patients identify and implement strategies to improve their psychosocial health and enhance their quality of life (QoL). Children's hospitals face important decisions about how best to address the psychosocial needs of their patients. Hospitals are increasingly weighing the reality that caring for adolescents' chronic illnesses requires incorporating strategies to address their QoL.(1-4) Moving toward a more patient- and family-centered approach to care, some hospitals have begun to offer patients in the inpatient setting various activities that seek to enhace their QoL. Some hospitals offer visits from volunteers, pet therapy teams, opportunities to do arts and crafts, exercise classes, and the ability to choose from a library of books and movies, among many other options. Even with an increase in these offerings, the extent to which hospitals offer programs and services to patients can vary widely.

Assessing the prevalence of chronic diseases in the U.S. by region, a recent study found the Mid-South population had increased rates of chronic disease when compared to the rest of the U.S. population.(5) This region had the highest percentages of adult and pediatric obesity, diabetes, high blood pressure, and stroke, specifically. The management of and prevention of chronic conditions in children and adolescents has the ability to reduce unnecessary healthcare utilization and maximize health outcomes. Given the increased prevalence of chronic disease in the South, the analysis targets the offerings of children's hospitals in the southeast region.

The first half of this chapter summarizes the inpatient offerings available to adolescents at 11 children's hospitals in the southeast U.S. with a focus on programs that target specific predictors of QoL or HRQoL identified in Chapter 2. Among the seven predictor identified in the literature, four were most often cited by adolescents: the use of coping strategies, psychosocial

factors, disease management and treatment, and the mental health status of the adolescent. (Refer to Table 3.0 in Chapter 2.) It is expected that all hospitals would state that they seek to provide quality, evidence-based, clinical care from the standpoint of disease management and treatment. Given this assumption, the review of hospital offerings will highlight those programs which are geared toward addressing the following three predictors of QoL or HRQoL: use of coping strategies, psychosocial factors, and the mental health status of the adolescent.

The second half of the chapter offers a case study, delving more into one of the inpatient programs, Streetlight, offered at UF Health Shands Children's Hospital in Gainesville, Florida. Given Streetlight's specific focus on adolescents and young adults, broad engagement with patients regardless of chronic illness diagnosis, and 14-year operations as a 1:1 peer support program, providers and staff at UF Health Shands may be able to offer a more comprehensive insight on dolescents and young adults than their counterparts at the other hospitals. Further, given the eligibility criteria includes all certain chronic conditions, providers of varying backgrounds may offer insight across a broader population of adolescents and young adults than the other programs. Streetlight at UF ealth was selected because it has been operational for a long time, enrolls students from a variety of disciplines, focuses on adolescents and young adults, and serves adolescent patients with a wide range of chronic conditions.

3.2 Methods

The sample of 11 hospitals includes those within the Southeast region that raned among U.S. News and World Report's top 50 for 2018-2019, specifically for treatment of pediatric cancer. The methodology U.S. News and World Report employed did not examine any other chronic diseases.(6) Each of the 11 hospitals scored the maximum number of points for offering

"advanced palliative care" services to children and adolescents.(6) Out of all categories scored to determine rankings, this one is most likely to include assessment of QoL-related services.

The targeted review of 11 hospitals' offerings was first conducted according to publicly available information on the hospitals' websites. When possible, specific pages related to inpatient programs and offerings were utilized to gather this information. Searches were performed within each site for the following terms: inpatient program(s), adolescent(s), peer(s), family suppor, palliative care, and volunteer. To ensure the accuracy of this summarized information, phone conversations were conducted with each of the hospitals. Using a semi-structured interview approach, they were asked to review the information captured from the hospital's website and offer descriptions of any additional inpatient programs offered to adolescents that were not captured. In all case, the office of Child Life was contacted first, since this program was common across hospitals, and because Child Life therapists typically engage with other departments and services in the provision of care to patients. If there was no response, a voicemail was left. If the call was not returned within three business days, another call was made to the same office and an email was also sent to the central Child Life email provided or to the Director of Child Life, whichever was available publicly on the website. This process was repeated after 5 more business days, in hopes of connecting with someone on the phone.

Out of 11 hospitals, phone interviews were successfully conducted with nine hospitals. St. Jude Children's Research Hospital and Monroe Carell Jr. Children's Hospital at Vanderbilt did not respond to emails or phone calls, after 3 total attempts. Among the other nine, representatives were familiar with the hospital's program offerings and provided detailed explanations, responded to questions, and offered other programs that fit the criteria and may have not been included on the website. Criteria included: being offered to adolescents with

chronic illnesses, being offered in the inpatient setting, and seeking to enhance QoL. After the phone conversations, the summary table was modified to include edits and additional information not captured in the initial website review. Refer to Table 1.0 (overview) and Tables 2.0 – 12.0 (detail, by hospital).

The inpatient program offerings summarized are in addition to the services provided by social workers, case managers, clinical psychologists, and other key members of the patients' integrated care team who, in addition to coordinating care, seek to maximize QoL for the patient and/or their families. Because these services are offered as part of clinical care coordination across institutions, they are not included in the summarized program offerings. Their value, however, is not to be overlooked in terms of the impact they are able to make in their roles. They often go above and beyond to ensure patients are as comfortable as possible. They raise issues with clinicians as they observe them, and are seen as advocates in many cases. The additional services described herein are resources they typically draw upon in seeking to provide the best quality, patient-centered care possible.

Of note, each hospital offers a variety of inpatient and outpatient programs, or provides referrals to programs for patients transitioning to the outpatient setting. Because this thesis focuses on those programs offered in the inpatient setting, those that were solely provided in the outpatient setting are not included in this summary. Certain programs are offered to all pediatric patients broadly, and others are offered to specific age groups or subsets of the inpatient population based on diagnosis (i.e., cancer support groups, etc.). If not specified in Tables 2.0 – 12.0, the program is offered broadly. Otherwise, the targeted adolescent population is specified.

3.3 Review of Children's Hospital Offerings

<u>Similarities/Consistencies across Inpatient Programs Offered</u>

3.3.1 Child Life Therapy

Child Life Therapy is offered across all 11 hospitals. Child Life specialists are specifically licensed in helping patients and families navigate the process of an illness.(7) They are part of the integrated care team in the inpatient setting and often work alongside physicians, nurses, social workers, psychologists, and others. Across all 11 hospitals, Child Life specialists document a summary of their visit with the patient in the electronic health record, which can be viewed by other members of the care team. Child Life models may vary slightly across hospitals, but typically offers patients age-appropriate education about medical procedures, opportunities for distraction from a treatment or procedure (books, music, movies, etc.), and variations of play and recreational therapy. Child Life programs at certain institutions allow trained volunteers to serve alongside them, assisting with activities such as playing games with patients, cleaning toys, answering phone calls, or helping patients' families navigate the hospital. Volunteers are typically randomly assigned to tasks, and do not typically partner with patients or establish peer-based relationships with them. When Child Life assists with preparations for medical procedures or any activity that involves protected patient information or might be sensitive to the patient and/or family's wishes, a Child Life specialist manages the case rather than a volunteer.

Certified Child Life specialists operate according to six domains to develop interventions to meet the needs of the children they serve. These include: 1) an individualized approach to care, 2) a focus on cultivating resilience, 3) cognizance of the developmental contexts in which children and families live and grow, 4) consideration for the impacts of past and present trauma, 5) establish and develop therapeutic relationships, and 6) capitalize on the utility of play therapy.(8) Child Life specialists are able to operationalize their training and expertise to help the clinical team anticipate patient responses to healthcare experiences.

Adolescent involvement with Child Life Therapy has shown to be linked to long-term improvements in psychosocial well-being, illness knowledge, and treatment adherence. In addition, across children of all ages, engagement with Child Life Therapy drives effective outcomes for hospitals by optimizing resources and limiting waste, resulting in a positive return on investment (ROI) to the hospital, when looking at reallocation of anesthesia and staffing resources. Interviews with hospitals illuminated the notion that younger children are typically willing to engage in Child Life activities, and that adolescents are sometimes more hesitant to engage with specialists.(9-11) Nevertheless, children's hospitals uniformly offer Child Life Therapy as a means to help patients learn and engage in their care, while seeking to alleviate the stress and anxiety of the inpatient setting.

3.3.2 Pet Therapy

All 11 hospitals also offer visits from certified animals and their handlers. These teams often undergo specific training, and are widely managed by the hospitals' office of volunteer services. At some hospitals, Child Life specialists are also certified dog handlers. Depending on a patient's illness, course of treatment, and location within the hospital, some patients may not be eligible for a pet therapy visit.

Animal-assisted therapy has increasingly been studied in the last two decades.(12) Studies have shown that interactions between the patient and animal provide a context which improves communication, reduces symptoms, elevates self-confidence, and improves overall quality of life. As research has demonstrated the positive impacts, children's hospitals have expanded offerings to allow trained and certified animal handlers visit with patients.

3.3.3 Art Therapy

Of the 11 hospitals surveyed, all offer some form of art therapy. Programs vary widely across hospitals, but all seek to offer distraction to patients and families in the inpatient setting. Art therapy involves creative techniques such as drawing, painting, sculpting, and coloring to help individuals express themselves, relieve stress, and cope with an illness. Over the past two decades, psychologists have begun to research how creative expression may impact healing emotional injuries, increasing self-understanding, reducing symptoms, and altering behaviors.(13) Among samples of patients with chronic illnesses, studies found that art distracted patients from thoughts about their illness,(14) improved their expression of grief,(14) improved their well-being by decreasing negative emotions,(15) and reduced stress and anxiety, among other positive findings.

3.3.4 Music Therapy

All hospitals surveyed also offered some form of music therapy to adolescents. Depending on the case, it may participatory involvement (i.e., adolescents are helping to make music) or more performance-based involvement (i.e., musician performing in a patient's room). Regardless, the use of music and rhythm in the therapeutic treatment of patients with chronic illnesses has shown to alleviate the burden and high cost of conventional treatments(16) and has shown to increase overall patient satisfaction.(17) Some hospitals employ music therapists, and others seek talent from local volunteers.

3.3.5 General Hospital Volunteer Programs

Each of the 11 hospitals also offers a volunteer program, which involves providing services to and/or interacting with adolescents with chronic illnesses. In some cases, this is distributing books, games, and movies, room-to-room. In other cases, volunteers offer to play games and spend time with patients, either in their room or in a common area. Finally, most

hospitals utilize volunteer assistance to clean toys, answer phones, and perform other administrative functions. At some hospitals, volunteers are trained and/or supervised by the Child Life department. They are typically placed according to areas of need, and must be flexible as no two volunteer shifts may be alike. It is not expected that volunteers will encounter patients and/or families on a repeat basis, as would typically be the case in a 1:1 peer support program, for example.

The hospitals included in the sample range in size from 88 to 332 inpatient beds. Seven of the 11 hospitals are academic medical centers. All seven offer undergraduate students the opportunity to volunteer, regardless of field of study. Some universities encourage students to volunteer as a way to engage in the local community. According to interviews with hospital representatives, the academic medical centers have no shortage of students interested in volunteering. This has also been found to be true among volunteers for 1:1 peer support programs.

3.3.6 Pastoral Care/Spiritual Support

Pastoral care services, typically offered a chaplain, are offered across all hospitals. In most cases, these services are included as part of the clinical care team, alongside social work, psychologists, care managers, and Child Life Therapy. According to interviews with hospitals, adolescents do not commonly utilize these services to provide ongoing psychosocial support, particularly if they do not have a spiritual background or strong interest in religion.(18) Across hospitals, patients who are receiving news of a terminal or late-stage diagnosis will be offered supportive care from a Chaplain, who can help the patient and family process the news.

3.3.7 Dedicated Activity Room(s) for Teens

Eight of the 11 hospitals offer adolescents a dedicated activity room, often referred to as a "teen room" or "teen lounge." Sometimes referred to as "safe spaces," they are also free of interactions with clinicians and medical procedures. In some hospitals, these rooms are located on units that are specific to adolescents. In others, there are age-specific activity rooms throughout the hospital, as units may be disease-specific but not age-specific. Teen rooms typically have video game set-ups, comfortable chairs, stereo systems, pool tables, fuse ball tables, and other fun activities. These spaces create a natural setting for adolescents to meet other similar-age patients while in the hospital, without the presence of a volunteer.

3.3.8 Hospital School Program

The combination of managing a chronic illness and the related symptoms, absence from school, and falling behind academically can be potentially damaging for adolescents.(19) Of the 11 hospitals surveyed, 8 offer formal services for schooling or tutoring while adolescents are in the inpatient setting. While this does not afford them the opportunity to socialize as they would in a school setting per se, it can add a structured routine and perhaps a sense of accomplishment, as adolescents are able to keep up academically with their peers at school.(19) Hospital school programs all support parents in navigating the educational system, making the transition from hospital back to school as smooth as possible.

Differences across Inpatient Programs Offered

3.3.9 Integrated Clinical Psychosocial Care Team

Given the increasing shift toward integration and coordination of care across the continuum, these clinical teams are becoming more popular at children's hospitals.(20) These integrated psychosocial care teams are often specific to an illness or disease category (e.g., hematology/oncology, oncology, palliative care, burns, etc.) and are slowly forming at certain

children's hospitals. The team often rounds at the same time as the primary service team for which the child was admitted. They help to drive the patient's care plan development and document progress notes in the electronic health record, similar to others on the care team. Multidisciplinary models are organized to address comprehensive and myriad factors associated with a patient's condition. Teams can consist of mental health professionals, psychologists, social workers, spiritual care providers, physicians, nurses, and other specialized clinicians. Teams may offer various benefits tailored to disease-specific needs, but most often include assistance navigating the complexities of the healthcare continuum, assistance with transitions from inpatient to outpatient settings, establishment of home care services, assistance with disease-specific education, linkage to other families and patients who might serve as mentors, as well as referrals to community resources and support groups.(20)

An example of one such program at Children's of Alabama is there Hope and Cope Psychosocial Program offered in pediatric hematology-oncology. They offer a comprehensive list of therapies, including music, art, pet, gardening, as well as support groups for parents and family members.(21) The program's director is grateful for the support and advocacy for the program at Children's of Alabama. Philanthropic and grant support play a critical role in ensuring the program is sustained year-to-year.(21)

3.3.10 1:1 Peer Support Programs with Student Volunteers

Some children's hospitals offer specialized 1:1 peer support programs to adolescents in the inpatient setting. Among the 11 hospitals surveyed, three hospitals offer such programs – Wolfson's Children's, UF Health Shands, and UNC Children's. One-to-one peer support programs provide adolescents with chronic illnesses the opportunity to talk and spend time with other young people who are likely to relate to their concerns.(22) Each of these institutions offers

slightly different models. The second part of this chapter will focus on the Streetlight program at UF Health Shands, specifically providing an analysis of patient's insights into the program's impact on their QoL. While 1:1 peer support programs appear to offer similar services as general hospital volunteer programs, 1:1 peer support programs typically allow adolescents and volunteers to partner together, establishing a relationship over time.

3.3.11 Family-to-Family Mentorship Program

Children's of Atlanta and Levine Children's are the only hospitals in this subset to offer a formal family-to-family mentor program for chronically ill adolescents. If desired, adolescents and their families are paired with other patients and families who confront similar health-related challenges. These connections may begin in the inpatient setting, and often continue in the outpatient setting.(9,23) These connections provide the opportunity to voice concerns, worries, and frustrations with others who might understand their situation.

3.3.12 Media Room/Radio Station

Another feature of some children's hospitals is a hospital-run media center or radio station. Support from philanthropists has contributed to the increase in these across some hospitals in the southeast U.S. The Ryan Seacrest Foundation, specifically, has helped to establish "Seacrest Studios" in 3 of the 11 hospitals in this subset (Atlanta Children's, Levine Children's, and Vanderbilt Children's). The Johns Hopkins Children's Center and Wolfson Children's also have their own radio station and television channels, which are operated largely by Child Life and volunteers. Children and adolescents who wish to learn more about media arts can participate in hosting their own shows "on the air," and producing short television spots. Patients throughout the hospital can watch and participate in these offerings through TV and radio features available in the inpatient rooms.

3.4 Gaps across Inpatient Program Offerings

Examining the various predictors of QoL or HRQoL for these specific categories (i.e., use of coping skills, psychosocial factors, and mental health status of the adolescent) identified in Chapter 2, some predictors are not encompassed in the offerings at all the 11 hospitals. Refer to Table 13.0 for a scaled-down version of the same table provided in Chapter 2. The offerings summarized are those provided in addition to the professional clinical care the patients receive. For example, patients received psychology and counseling supports as part of their care, so the addition of a program focused in that area may not be deemed as critical by hospital leaders.

In the category of psychosocial factors, specific predictors identified in Chapter 2 (refer to Table 13.0) related to the adolescents' relationship with their parents are not addressed by these programs. Specifically, adolescents' negotiation of parental conflicts, family functioning, and family adaptability are all shown to predict QoL among chronically ill adolescents. While it may not be reasonable to address these needs in detail during a shorter inpatient stay, these programs might consider whether there are ways to engage adolescents is staying connected with their families and improving communication with their parents. Programs might also consider opportunities to refer family members to resources in the community, or even connect them with a social worker or other parents of adolescents who might be able to help address their challenges. Family-to-family mentorship programs may be helpful in this domain, but in this sample of 11 hospitals, only two (Children's of Atlanta and Levine Children's) offer formal family programs.(9,23)

The use of online social networks as a way for adolescents to engage with peers is largely unrepresented in the program offerings summarized. This may be due to the fact that there are a number of sensitivities around patient privacy and use of the internet, causing perhaps room for

more concern than benefit. Hospitals might not be able to assure safety and confidentiality. Further research might help reveal whether hospitals have developed systems for linking patients with similar diagnoses to each other, in online platforms, as a way to connect and seek support. While not the same as face-to-face interactions, this would be particularly useful for adolescents who are immunocompromised or otherwise unable to be around others.

Adolescents also cited dating anxiety, sexual adaptation, and development of romantic relationships as predictors of QoL. Again, while it may not be reasonable to address this in detail during an inpatient stay, hospitals and providers might consider offering clinical support in navigating their emotions around dating. This also ties to anxiety about telling peers about their illness and worrying about public perceptions of their disease, which were also predictors. Peer support programs, in which volunteers are generally supportive of the adolescents, not easily fazed, and help to normalize an adolescent's circumstances (i.e., medication regimes, treatments, visible differences in appearance) may help ease the burden associated with these feelings. That said, a more direct approach to addressing these factors might be helpful as adolescents work to address their struggles.

One of the striking realities is that the predictors summarized from the literature are largely focused on the adolescent's mental health and ability to cope with their circumstances. The availability and use of dedicated psychologists, social workers, and spiritual supports should be further examined. Interviews with hospitals revealed that dedicated psychology and psychiatry resources are not always available by unit.(9,21) In some cases, clinical care teams must request psychology consults for patients who are exhibiting depressive symptoms, for example. The establishment of an ongoing therapeutic counseling relationship may be strained

due to limitations on the clinician's time, understanding of a particular diagnosis, or other factors, for example.

An adolescent's ability to use coping strategies as a mechanism to enhance their QoL is dependent on them knowing what coping strategies are and how they can use them. Further research on the modalities for teaching and engaging adolescents in learning and practicing coping strategies might help hospitals decide if and how they can better address this category of predictors.

Finally, self-esteem, body image, and satisfaction with life in general are all shown to predict QoL or HRQoL, as identified in Chapter 2. The categories of programs offered do not readily address these aspects of identity. Rather, interventions such as art therapy, music therapy, and even playing a game with a volunteer offer more diversion than direct reckoning with issues of self-esteem. While these offerings may help adolescents gain confidence or distract them from feelings of isolation or loneliness, they are not necessarily working to address the deeper issue at hand. That said, these may be the most appropriate interventions given that relationships with counselors and therapists may not extend beyond an inpatient visit. Even still, hospitals might consider tailoring programs, with clinical guidance, to focus on these categories more directly. Similarly, volunteer peers could be specifically trained in understanding how to navigate issues of self-esteem and self-identity when engaging with adolescents.

3.5 Reflecting on Experiences Prior to COVID-19

Interviews with representatives across hospitals revealed timely insights about the current state of program offerings available to patients. Given the impact of COVID-19 across the U.S., all hospitals in this sample began discontinuing the use of volunteers in March 2020. The interviews were conducted in July 2020, marking approximately 4 months without being able to

offer many of these inpatient programs. Interviewees commented on the toll this has had on patients, especially those who had become accustomed to the programs. Further, interviewees noted the challenges this posed to hospital providers, clinicians, child life therapists, and others who felt they did not have adequate time to spend with patients given multiple competing priorities and a lack of resources. Most hospital representatives were under the impression that program offerings might slowly resume as infection rates decrease, and expect volunteers to be back in the inpatient setting once a vaccine has been developed.

3.6 Case Study: Streetlight at UF Health Shands Children's Hospital

3.6.1 Background

As discussed, three hospitals among the 11 examined in this work offer 1:1 peer support programs in the inpatient setting. (Refer to Table 1.0.) Among these are the Emerging Pediatric Professionals (EPP) program at Wolfson Children's, the Carolina Pediatric Attention Love and Support (CPALs) program at University of North Carolina Children's Hospital, and Streetlight at the University of Florida Shands Children's Hospital.

Three hospitals included in the review offer a 1:1 peer support program to adolescents in the inpatient setting (refer to Table 1.0). These include Wolfson Children's (Emerging Pediatric Professionals – EPP), UF Health Shands Children's Hospital (Streetlight), and University of North Carolina Children's Hospital (Carolina Pediatric Attention Love and Support – CPALs). These programs seek to achieve the same mission of offering companionship, distraction, and a sense of normalcy to the inpatient setting. While all are offered to adolescent-aged patients, Streetlight is the only program that targets adolescents and young adults specifically. Patients are eligible to participate in Streetlight only if they are between the ages of 13-29.(18) CPALs and EPP are open to pediatric patients of all ages. Streetlight and EPP serve patients of all chronic

illness diagnoses, while CPALs partners with patient who have a diagnosis in hematology/oncology only.(24) The programs have also been in existence for different amounts of time. CPALs has been operating for 25 years, though the program as it operates today was largely formed in the last decade.(24) Streetlight has been operational for 14 years.(18) EPP has been operational for approximately a year and a half.(10)

University of Florida and University of North Carolina advertise these volunteer opportunities to undergraduate students, especially targeting those in pre-health majors. Streetlight has been operational for 14 years,(18) and CPALs has been running for 25 years, though the program as it is known today was largely formed in the last decade.(24) Though not an academic medical center, Wolfson Children's partners with nearby University of North Florida to offer students in their School of Nursing the opportunity to partner with patients over the course of a semester. The EPP program has been operational for a year and a half.(10)

These programs are similar in that they offer companionship, distraction, and a sense of normalcy to pediatric patients the inpatient setting. While all are offered to adolescent-aged patients, Streetlight is the only program tailored to adolescents and young adults specifically.(18) Patients are eligible to participate in Streetlight only if they are between the ages of 13-29.(18) CPALs and EPP are open to pediatric patients of all ages.(10,24) Streetlight and EPP serve patients of all chronic illness diagnoses, while CPALs partners with patient who have a diagnosis in hematology/oncology only.(24) Given Streetlight's specific focus on adolescents and young adults, engagement with patients regardless of diagnosis, and 14-year operations as a 1:1 peer support program, providers and staff at UF Health Shands may be able to offer a more comprehensive insight on adolescents and young adults than their counterparts at the other hospitals.

Streetlight is an adolescent peer support program offered in the inpatient setting at UF Health Shands Hospital in Gainesville, Florida. It was founded in 2006 by Rebecca Brown, who sought to develop a unique palliative care program based on the findings of her thesis work as a seminarian.(25) Still in operation today, Streetlight is offered to patients ages 13-29 living with chronic and life-limiting illnesses.(25) Adolescents are able to navigate through the course of their illness with psychosocial and spiritual support offered by the Streetlight team.

Streetlight staff, including a director, assistant director, and 2 part-time support staff, have education and experience in palliative care, end-of-life support, and thanatology.(18) Streetlight volunteers are undergraduate students at the University of Florida, seeking to gain experience at the bedside in a non-clinical role. Volunteers are selected annually through an extensive interview process, in which they must 1) demonstrate a passion for helping hospitalized adolescents, 2) have at least one strong written recommendation for a healthcare professional, professor, or character reference, 3) commit to the program for two years or more, and to at least 3 hours of service weekly, and 4) meet all other requirements as prescribed by the UF Health Shands volunteer office (i.e., immunizations, etc.).(18)

A 2015 study looking at the impact of Streetlight on the students serving as volunteers revealed that they felt their involvement in the program increased their ability to understand how others experience a chronic illness.(26) It also enhanced their ability to cope with and communicate about end-of-life issues.(26) Volunteers reported that the program had a significant impact on their sense of empathy, compassion, and comfort.(26) The authors concluded that the Streetlight model may be a viable model for exposing students to compassionate, psychosocial, palliative care.(26)

In some cases, adolescent patients who once received Streetlight support in the inpatient setting become Streetlight volunteers as a way to "pay it forward" and because they seek volunteer experience in the hospital.(18) In most cases, they are also college students at University of Florida.(18) Similarly, some Streetlight volunteers are managing chronic illnesses or conditions of their own, and seek opportunities to provide support and guidance. While neither of these is a requirement to become a Streetlight volunteer, their ability to relate to patients and their empathetic nature may be influenced by their personal circumstances.

This case study focuses on patients' perspectives of Streetlight, specifically assessing the extent to which the program impacts three categories of predictors of QoL or HRQoL – use of coping strategies, psychosocial factors, and their mental health status. These categories were identified in the literature review in Chapter 2. Coping strategies describe an individuals' conscious effort to address personal and interpersonal problems in response to distress or discomfort. Most of the coping strategies that were found to predict increased QoL were emotionally focused (Refer to Table 13.0). Some adolescents utilize clinician-led therapy as a coping strategy and a way to better understand their emotions and behaviors. Psychosocial factors include an individual's interpersonal relationships and social environment. For adolescents, this includes aspects of social support, school participation, family dynamics, dating and romance, and identity and independence. During the transition from childhood to adulthood, a sense of identity and autonomy is developed. This can simultaneously impact the adolescent's mental health status, especially from the perspective of an adolescent with a chronic illness. As they develop and mature, some adolescents become increasingly focused on body image, for example. Among adolescents who are more socially isolated, depression and anxiety may play a role in navigating their journey toward wellness. It is important that these categories of

predictors of QoL be examined within program offerings to understand how adolescents are currently supported as well as to identify gaps in their support.

3.6.2 Study Design and Population

This is a qualitative evaluation of patients' perceptions of the Streetlight program's impact on addressing their use of coping skills, psychosocial factors, and mental health status. These are three categories of predictors of QoL or HRQoL among adolescents with chronic illnesses, as identified in Chapter 2. Qualitative patient interviews were previously conducted by a research team at UF Health as part of another study, and this is a secondary evaluation of the data. Their primary objectives were to assess the overall well-being of patients who had received Streetlight services, to evaluate their QoL, and to gain insight into patients' specific experiences with the program in comparison to other supports they receive at UF Health. In contrast, this analysis utilizes the same interview data to understand how Streetlight addresses predictors of QoL that are categorized in terms of coping skills, psychosocial factors, and aspects of mental health. This adds an important contribution to the limited literature on adolescents' self-reported predictors of QoL and the extent to which inpatient programs are tailored to address them.

This study includes 9 patients who engaged with Streetlight during one or more inpatient admissions at UF Health Shands Hospital. The research team at UF Health conducted interviews with 9 current and former patients who had engaged with Streetlight and agreed to be contacted after completing an initial paper-based survey that was sent to all current and former patients who had interacted with Streetlight. Their intent was to interview up to 25 patients, however they were only able to recruit 9 individuals. While they identified and outreached more than 25, they had difficulty recruiting patients to participate in interviews – many missed phone calls and did not respond to emails. All interview transcripts were included in this secondary evaluation of the

data. Table 14.0 provides a summary of their related demographic and hospital stay information. The average age of the individual at the date of the interview was 22.4 years, with 4 individuals identifying as female and 5 identifying as male. They had an average of 7 hospital admissions, from the first time they were introduced to Streetlight to the time of interview. Their average length of stay (LOS) per admission was 9 days, and the maximum LOS average was 27.3 days across all 9 individuals. On average, those interviewed engaged with Streetlight between 5 and 162 times (average of 42) since being first introduced to the program.

3.6.3 Methods

The interviews were conducted and recorded by a research team at UF Health. They followed a semi-structured interview format using an interview guide, asking the same questions of each interviewee. They utilized open-ended questions to guide the discussion. While not all of the questions posed were directly relevant to the predictors of interest in this study, the data were analyzed in their entirety so as to be as comprehensive as possible.

The analysis follows a general thematic analysis approach, as outlined by Braun and Clarke.(27) Braun and Clarke outline a series of phases to guide researchers through thematic analysis, helping to make the process replicable and transparent. This process includes familiarizing oneself with the data, generating a series of initial codes, analyzing the initial codes for natural groupings or themes, conducting an in-depth review of the themes, combining and assigning names to themes, and finally analyzing whether there is a series or hierarchy to the themes.(27) They describe themes as capturing important aspects of the data in relation to the research question, and representing some level of patterned response or meaning within the data set.(27)

Following this approach, the transcripts were analyzed using MAXQDA Analytics Pro 2020 (Release 20.1.0). First, transcripts were read in detail several times in order to obtain an overall sense of the content. Next, the transcripts were examined slowly, coding sections of text that revealed important patterns in patients' insights (subthemes) as they related to the three categories of interest – use of coping skills, psychosocial factors, and mental health status. Once all interviews were coded, subthemes were compared and combined if they represented similar ideas or thoughts. For example, one subtheme identified was "I am tired of watching TV all day" and another was "watching TV shows is boring." These were combined to form the subtheme "watching TV all day is boring." Next, subthemes were formed into groups. For example, "watching TV all day is boring" and "I feel lonely/isolated" both describe how the adolescents feel about the hospital environment. In this case, they both fit under the theme of "hospitals are boring, isolating, and hard." Sub-themes and themes were compared with the UF research team, who used the interview data for separate analyses, for purposes of validating the coding methodology to ensure they were not vastly different. Similarly, a faculty member at the Johns Hopkins School of Public Health who is well-experienced in qualitative research and MAXQDA reviewed the codes. All 9 transcripts were included in the analysis. Saturation was achieved in the interview data after the 6th transcript was coded. No new themes were revealed after this transcript.

In order to understand whether there might be a difference in themes depending on the number of Streetlight encounters, a comparison was done between the two interviewees who had the fewest and most SL encounters. This offers insight into impressions that patients have early on versus those they develop over time, with more involvement in Streetlight. Unfortunately,

without a larger sample of interviewees, it is not possible to draw conclusions about adolescents who have many versus fewer Streetlight encounters.

3.6.4 Results

A thorough review of the interview data revealed a variety of themes and sub-themes in alignment with the categories of interest – use of coping skills, psychosocial factors, and the mental health status of the adolescent. In each category, there were also themes related to how Streetlight helped address the predictors of QoL within the themes. Similar to the literature review in Chapter 2, there was greatest diversity in predictors of QoL or HRQoL in the psychosocial factors category. This category encompasses themes focused on school involvement, interpersonal relationships, involvement in in-person activities with peers, and friendships/bonds. Themes by category and related sub-themes are captured in Tables 16.0, 17.0, and 18.0. Streetlight-specific themes appear in the right column and are aligned with the relevant theme and subthemes. Select, relevant quotes from interviews are summarized in Table 19.0.

<u>Use of Coping Skills</u>

1. Theme: Hospitals are boring, isolating, hard

Adolescents provided comments about the hospital setting being boring, isolating, or otherwise difficult to be in. They sometimes felt "stuck" and "lonely, isolated." One subtheme was "watching TV all day is boring," perhaps suggesting they felt watching TV was one of their only outlets. "…being in a room without, you know, what you're comfortable with…it gets tough." "And, you know…even on the pediatric floors…there really wasn't a lot to do." They also described the uncomfortable setting, including strange noises and annoying alarms, painting a picture of situational discomfort amidst the physical discomfort related to their illness. Some acknowledged that family members, nurses, social workers, and others were often busy and did

not have time to chat with them. Even so, they sometimes felt these people were their friends and family, especially those who experienced longer inpatient stays. “It’s lonely because parents and volunteers, and nurses…right, the nurses have a job to do and can’t always be there.”

2. Theme: Adjusting to being away from home

Adolescents also offered a variety of comments related to coping with the transition to a new setting away from home. “It was already challenging, itself, you know…going away to college. And then you add on, you know, getting a diagnosis.” This transitional time in life can be particularly challenges for adolescents who are forming their identity and sense of autonomy. In some cases, adolescents described how their care team in the hospital “makes me feel like this is my second house at my second home.” Without many of the physical comforts and, often, without the same amount of social support from friends and family, being away from home was described as adding to stress and general feelings of not being in control.

3. Theme: Adjusting to managing/coping with my illness

Adolescents also described the adjustment they were making in learning to manage and cope with their illness, and the challenges it presented. Coping with pain was mentioned repeatedly. Patients noted the impact of their physical pain on their ability and willingness to interact with others in the inpatient setting. “It was very difficult… like, you know, making friends, spending time with people because I was always in pain.”

Some interviewees discussed reintegrating back into social settings after undergoing treatment or procedures that left them with visible changes (i.e., wound vacuums, bandages, ports, etc.). One person recalled signing up to be a camp counselor the summer after she had left the hospital after weeks in the inpatient setting. “I had to have my pump going for my tube. I had to get fluids in and I had to get nutrition and I was going to keep up with everything that we were

doing." The pump made noise, and it began to bother the other girls in her cabin at night. "I shoved it in the corner of my bed away from everyone, and I shut my alarm off on it, so I tried my best to keep as much noise down. But, this girl, she went off on me, and she later apologized. But that situation has always stuck with me. So now I'm always really self-conscious…and you know, I don't do sleepovers anymore because of it." Stories such as these illustrate the ways in which adolescents are not only adjusting to managing the physical aspects of their illness, but also the emotional factors as well.

4. Theme: Streetlight keeps me company

Interviewees provided insights into how Streetlight volunteers kept them company, often providing distraction from the medical setting, being a source of fun, and giving them something to look forward to. "...we can share similar stories or tell me where they've been and it wasn't all just focused on how I feel and doctors…and what was going on." One adolescent said of Streetlight, "without [it], it would be like a lot more boring. I wouldn't have a break in the day. It would just be a continual cycle of nothing." Another said, "You know, without Streetlight, like that's a long time to be in the hospital and really not have, you know, people there." "[Streetlight] made the hospital experience just suck less." Adolescents described Streetlight volunteers as stopping by regularly, even if they had declined a visit the day before. They painted a picture of Streetlight's persistence and regularity, which is notable in the context of other feelings related to adjusting to new settings and feeling as though they have little control over their situation and environment.

5. Theme: Streetlight helps ease the burden

Adolescents described ways in which Streetlight helped to ease their burdens, making difficult days or procedures more manageable. This included stories about the ways Streetlight's

presence helped to ease their anxiety, build their resilience, and how Streetlight helped to create a nice atmosphere in their room. Adolescents also described how Streetlight helped life be normal. One patient recalled a time when her care team had difficulty placing an IV. "[Streetlight] sat there while I was getting the IV….it was very painful....she sat there and pulled up pictures of dogs on her phone. I love dogs and she tried to distract me, and you know, make sure I was…as comfortable as I could be…" In another example, a boy says "They would come by, and you know, I really like music. And one of the Streetlight people found out about it and came by and we just sat and watched music videos, and you know, that really helped because it was really nice…and I just got the abdominal port placed and it was extremely painful. So just being able to, you know, sit with him, it really helped."

Psychosocial Factors

1. Theme: Family involvement in care

Interviewees discussed the role their family plays in their care, and specifically their inpatient stay. Some described that their family cannot always be with them in the inpatient setting, often having to work and/or take care of other siblings. One adolescent simply said, "they don't have enough time." They also described how, even if their family is able to be present with them, "not every patient has the close family bond that you might expect." They described how not everyone is comfortable sharing their emotions and feelings with family, and sometimes lean on supportive friends instead. In other cases, adolescents sometimes "grew tired of [their] parents, you know, I just needed a break." "I love my mom so much, I do, but you know sometimes we have to try to be nice to each other. So it's nice to have a break. You know, for both of us." Family involvement, regardless of frequency or closeness, was described as consistent. In other words, they described their involvement as "I know what to expect from

[them]," which might suggest a feeling of control or certainty in the midst of other feelings of uncertainty or lack of control over their constantly changing circumstances.

2. Theme: Friends

Another theme consistent across all 9 interviewees was focused on friends. They described how they long to be with friends and how it often doesn't help to look at social media platforms because they see pictures of their friends hanging out and they realize they are missing out. Some adolescents talked about the friends they had made in the inpatient setting, saying they often met in common areas and discovered they had shared interests (i.e., video games, similar taste in music, etc.) Another subtheme was related to friends not understanding their circumstances, making it difficult to spend time together. "My friends go out and eat burgers and fries, all greasy foods, and I can't participate with them because it makes me sick. They look at me and I look fine. And I'm telling them I can't because, you know, I have this food intolerance, and they don't understand what food intolerances are, and I've tried explaining it to them, but they don't' get it. It's hard."

Some described opportunities to hang out in small groups in the hospital, often orchestrated by Child Life or Streetlight, and the sense of normalcy that created for them. All interviewees specifically described friendships and connections with Streetlight volunteers. "[We] rely on these volunteers to be kind of [our] friends and [our] right hand man throughout [our] treatment. That's what I know Streetlight as." One interviewee mentioned the "bond" they had with Streetlight volunteers multiple times throughout their interview. "It is kind of nice knowing that you have these people that you've kind of never met before, but you form this fresh bond with them."

3. Theme: Transitions are tough

Interviewees described the back and forth nature of some transitions that made it difficult to adjust to a new setting or set of circumstances. This theme included subthemes describing transitions between the inpatient and outpatient settings, from pediatric to adult care, going into and out of school, and the mental transition between being a teen and being chronically ill. "Everyone [at school] is just trying to see where they're fitting at that point in life and you're kind of stripped from that, you know, back and forth, in and out of school." The feelings of moving between two different settings were described as feeling uncertain and sometimes unexpected. Some adolescents described this as leading them to be anxious or nervous. "The first time when [the anxiety] was really bad – I'd stay in the hospital inpatient for months at a time. Overall, the treatment took like a year and a half – and obviously, going in and out of the hospital, inpatient to outpatient, it was too much."

4. Theme: Streetlight is like a family

Complementary to the theme of family involvement in care, adolescents also offered feelings of Streetlight being "like a family" to them. They specifically described the ways in which Streetlight volunteers "went out of their way" to understand their feelings, and the reliability of Streetlight volunteers in dropping by to check on them, or serving as "good listeners" when they needed it. Similar to the impression of family members' involvement in their care being consistent, so was Streetlight's presence. The support offered by Streetlight volunteers made them feel as though they had "other people on [my] team." "[My dad] lives, you know, 30-40 minutes away so he can't always come up here, but he knows at least I have company." One adolescent described how Streetlight offered her and her mom a chance to take a break. "Streetlight people will come and sit with you and try and interact with you. And that was a really great thing because you know talking to your mom for hours, on and on, you know, can

get kind of old. I love my mom to death, you know, but the same for her. It gives her a break, because she wants to be there with me, you know, and be there for me, but she knows when Streetlight people come she can go grab a coffee or something."

5. Theme: Streetlight is relatable/on my level

Adolescents repeatedly described how they felt Streetlight is "relatable" or "on my level." Similarly, most noted that the fact that Streetlight volunteers were "about my same age," which they described as being important in helping to foster connection with them. "[Streetlight] is mainly around my age. Most nurses [are] not so much around my age." Others commented on Streetlight's "persistence" and "creativity" in getting them to open up. "And at first I was very shy and closed off from Streetlight, you can ask [Streetlight director]. And [they'll] tell you [they] would try to talk to me and I just pretended I was asleep because I was just, anti-social, like I'm not talking to anybody. But [they] had the persistence to keep trying, keep trying, because they knew that, you know, being stuck in the hospital isn't good for me." Another common subtheme focused on the fact that Streetlight was "non-medical." "[They] are not necessarily focused on the medicinal side, but rather on the support and the care…and they try to keep your mind off the hospital." "…when you're constantly being examined by doctors and nurses and everyone coming into the room about serious matters…you know, they're all wonderful doctors and nurses, but they still have, you know, the doctor scrubs. And they're in there to check up on you and your health. And so [Streetlight] could come in and take your mind off everything which is so difficult to do…but they would somehow do it."

6. Theme: Recalling specific, positive, Streetlight memories/stories

Reviewing the transcripts, there was an overwhelming number of stories and memories adolescents shared about Streetlight. Some offered stories about specific volunteers, others

described how Streetlight helped them out of a slump, and all interviewees talked about the gratitude and appreciation they have for Streetlight in general. Given their desire to share, and the details they remembered in these stories, this theme serves to underscore the impact this program has on chronically ill adolescents.

Memories included recounting the first time they were introduced to the program, end-of-chemo celebrations the Streetlight team hosted, playing games together, hanging out in groups, listening to music, and many more. "…one time where [Streetlight] made a target practice in my room and the different targets were like cancer cells and different negative things that happened from the cancer." "…[Streetlight] always goes out of their way to find a movie…" "They always planned a big thing for birthdays…like, they know I love SpongeBob, and they made a big banner that said 19 years later, you know, with the dot, dot, dot, and there were all of the SpongeBob characters they had drawn and we hung them all around my room. So that's really cool."

In some cases, adolescents described how Streetlight helped them to engage more closely with their chronic illness community outside of the hospital. For example, Streetlight creates lists of local events and local organizations in Gainesville that serve individuals with the chronic diseases they encounter most often. "[They] linked me to them, and gave me this unique opportunity…to support other people who have CF, and I never had the opportunity to do that for others before."

Mental Health Status of the Adolescent

1. Theme: Agency/independence/sense of self

Adolescents described their agency, independence, and sense of self as impacting their QoL. "It's really easy to lose your identity when you have a chronic illness. It's really easy to

just lose a sense of who you are." Some described having their identity "stripped" from them. Others described how physical symptoms impacted their self-esteem and self-image too. "My wounds…just messed up my academics and social life and really, my self-esteem. I did the wound care myself during freshman year…and it was really bad. It really, really hurt my self-image."

Within this theme, adolescents described Streetlight volunteers as accepting them regardless, and not judging them. "Just being able to have a source of friends who were not going to judge. That was really impactful. We are just trying to have friends who are true, authentic friends, who accept our personalities, who accept our diagnoses, who accept everything that we are as a person."

2. Theme: Feeling down/depressed

Adolescents described feelings of depression and isolation that led to poorer QoL. "I had been getting very depressed, really low, because I had so many plans for the summer after my freshman year…things I wanted to do, especially with friends, but instead I had to be stuck in the hospital getting medications." There was also a sense of loneliness and neediness they expressed, especially in feeling like burden to others. "…you're laying in a bed, you get needy and the volunteers serve your needs, which helps the nurses out, you know, just from the non-medicinal side." "Sometimes I feel bad and guilty about [my] situation. I mean, there's nothing to fix the situation, though, there's nothing I can do to stop me from having this issue. So I feel like very helpless about it." These feelings of depression, loneliness, guilt, and helplessness describe predictors of poorer QoL that adolescents associate with the inpatient setting, their illness, or a combination of both.

3. Theme: Streetlight provides hope/joy/inspiration

In describing aspects of their mental health, all nine adolescents offered comments about Streetlight providing them hope, joy, and/or inspiration. “I mean, it’s not fun in the sense of, ‘oh, I just want to go into the hospital to see Streetlight’ but if I’m going to the hospital, I’m glad Streetlight is there.” Some even described Streetlight as part of their care, saying, “[Streetlight] has been very, very, very uplifting, very inspirational, kind of showing you what medicine is capable of doing. It has shown me that medicine is about nurturing and comforting more than even treating.” Another patient said “[At first], I’m done seeing new faces, and then their new faces enter the room and I don’t know how they will open up to me. But they did, and whatever they did, I’m glad they did it. It was magic. I don’t necessarily know [how to describe it] and I’m going to keep calling it magic because I generally don’t know how it works. But, it did work. And I’m very grateful to [Streetlight.” In some cases, Streetlight volunteers themselves disclosed to the adolescents that they, too, had a chronic illness. This was described as inspiring in that, “you know, they themselves, they are managing a chronic illness and still going to college. And eventually I want to try to go to college.”

Analysis of Potential Dose Effect

These analyses explore the potential for there to be a dose effect, or possible difference in the predictors cited by patients who had few encounters with the Streetlight team versus those who had many encounters. Table 15.0 presents hospital admission and Streetlight encounter data specific to the two interviewees who had the fewest encounters (5) and most encounters (162) with the Streetlight program.

Analyzing the themes presented by each interviewee, there are very slight, but notable differences in their comments. The patient who had engaged with Streetlight only 5 times (Patient A) during the course of 2 inpatient stays appreciated that Streetlight was offered, given

how boring the hospital can be. Similarly, she noted that the age of the volunteers made them more relatable, feeling as though they were able to relate to her. She felt the Streetlight team took the time to get to know her as a person rather than a patient. She commented that her family also appreciated Streetlight's support of her, and that she believed they too benefited from Streetlight during her 2 stays.

The patient who engaged with Streetlight 162 times (Patient B) over the course of 16 inpatient admissions made remarks within the same themes. He, too, was appreciative for Streetlight's relatability, noting that it was helpful that the volunteers were about his same age. His family was also involved in his care in the inpatient setting, and he believed they also benefited from Streetlight due to his involvement. Different than Patient A, however, Patient B went into much more detail recalling specific memories he had about interacting with volunteers. From dancing, to painting, to talking and telling stories, he spoke about many activities in great detail. He also made more comments, and repeated comments, about the fact that Streetlight let him be himself around them, getting to know him more than a patient. He spoke about the role Streetlight played in distracting him from the medical setting and various procedures.

While the differences are subtle, and many of the subthemes and themes are the same, a greater dose in this case could be suggestive, for example, of deeper connection and experience with Streetlight volunteers. This might be expected, as a longer duration of friendship and companionship might naturally lead one to have more specific memories over time. Across all nine interviewees, those who had the most encounters with Streetlight reflected on their time in the hospital more positively than those who had fewer interactions. This could be suggestive of a variety of possibilities. For example, Streetlight might enhance patients' QoL in the inpatient setting so much that, the more encounters, the more positively adolescents describe their

experience overall. Alternatively, individuals with more Streetlight encounters might not have experienced the same levels of depression and/or isolation that other adolescents did while in the inpatient setting, thus leading them to describe their inpatient stay in a more positive light. It is also possible that those who enjoyed spending time with a Streetlight volunteer were more likely to seek out the Streetlight team repeatedly, It is very difficult to control for potential confounders, and thus, leaving conclusions speculative. While they might provide insight into further research opportunities, they are not suggestive of conclusive findings.

The potential for a dose effect has implications for further work in assessing the impact of inpatient program offerings on patients' QoL or HRQoL. Among a larger sample of interviewees, it would be helpful to control for various factors to understand the extent to which a program's impact on an adolescent's QoL can be attributed to characteristics of the program itself.

3.6.5 Discussion

These findings complement the results of the literature review in Chapter 2, which were not specific to adolescents in the inpatient setting, but rather all adolescents with one or more chronic illnesses. Given that many of the same predictors were present among adolescents in the inpatient setting at UF Health, it would be important to study whether there are differences in predictors between chronically ill adolescents in the inpatient and outpatient settings. Further study in this area might include selecting a group of adolescents whose chronic illness is managed on an outpatient basis, and then selecting another group similar to the one in this sample, whose illness finds them often treated in the inpatient setting. It would be ideal to control for as many factors as possible (i.e., age, time with disease) so as to make comparisons across groups that might just reveal differences in their QoL. Future studies such as this might help

hospitals, outpatient centers, and healthcare providers hone in on specific predictors of QoL, enabling them to tailor programs to the patients' care setting.

Given the participants' comments and stories about the role of the Streetlight program, their perception suggests Streetlight impacts a wide variety of psychosocial factors. The results were slightly less ubiquitous in the categories related to use of coping skills and the adolescent's mental health status, with both fewer comments overall related to those themes and sub-themes, and fewer interviewees offering comments in each. It should be noted, however, that all 3 categories under review in this study have considerable overlap. Further, the notion of directly discussing issues around coping and mental health, for example, may carry stigma or otherwise be uncomfortable for adolescents to discuss openly with peers or interviewers. Given this, the various themes presented could be seen as spanning across all 3 categories, especially if examined in a deeper psychological context aimed at understanding hidden or unspoken messages. In other words, depending on the interviewee, recounting specific positive memories about dancing with Streetlight volunteers may extend beyond psychosocial factors and have implications for serving as a coping skill. Without truly knowing the deeper context of an individual's comments, it is difficult to determine how it should be categorized.

Taken into consideration as grouping of themes, and given the overwhelmingly positive response to the Streetlight program among these interviewees, 1:1 peer support programs should be considered as children's hospital continue to innovate to provide patient- and family-centered care. In particular, the added value of 1:1 peer interactions should be examined, especially in the context of potential benefits from informal counseling and/or companionship. Research has found that, while having friends (or volunteers) can play an important role in the life of a chronically ill adolescent, 1:1 peer support offers adolescents the opportunity for deeper

connections around their condition, and their specific circumstances, about which peers (with or without chronic illnesses) might relate.(22) The extent to which the programs may be mutually beneficial for patients and volunteers should also be more closely examined.

3.6.6 Limitations

There are limitations to this study. First, it is important to note that this study is restricted to data from interviews with 9 participants. A small sample size increases the likelihood of identifying themes in the literature that may not represent the viewpoints of chronically ill adolescents broadly. Given that saturation in the data was achieved after the sixth interview, and no new themes emerged in the data, the impact of this limitation is likely to be minimal. Further, participants who chose to participate in the study may have been different than those who did not participate, leading to a selection bias. Unfortunately, comparison data between the 9 participants who self-selected to participate and those who did not respond were not available. Three of the nine participants chose to serve as Streetlight volunteers themselves, after having received the Streetlight intervention in the inpatient setting. Given this, they may have biases about Streetlight that other patients might not have. Additionally, some of the interviews took place while the interviewee was hospitalized, and others took place up to a year after they had been discharged from Shands UF Health. Given this, there may be variation in responses due to recall bias. Similarly, interviewees may have felt pressured to provide socially desirable responses to the interview questions, and perhaps not share their honest critiques of the program. This would pose issues with response bias, and could potentially skew the data. As such, the interview guide was carefully developed to ensure wording was neutral and questions were open-ended, prompting interviewees to share honestly.

Finally, given that the literature review provided evidence for the predictors of QoL or HRQoL, it is possible codes were assigned to these predictors based on predetermined assumptions about groupings, without challenging the possibility of additional predictors. In this particular study, the coding was performed by one individual. To help ensure validity of the coding process, codes were compared with the UF Health research team and were also reviewed by a faculty member familiar with qualitative research at the Johns Hopkins School of Public Health. IRB approval for this study was obtained from both University of Florida and Johns Hopkins Bloomberg School of Public Health.

3.7 Conclusions

This chapter illuminates the ways in which hospitals seek to enhance the QoL and HRQoL of their adolescent patients. Adolescent patients are key stakeholders in their care, and it is important for hospital leaders and providers to understand the aspects of their care that they value most. It is also important to glean from them the features or enhancements they feel are missing, or the aspects of their QoL they feel need further attention.

The 11 hospitals in this sample group the inpatient initiatives listed in Table 1.0 together under the umbrella of pediatrics, regardless of the ages of patients they are serving. Child Life, for example, is typically offered across ages and, depending on the hospital, may tailor their intervention to patients based on age. Even still, these programs are not advertised as being age-specific. At first glance, an adolescent might view a "pediatric" program as serving the interests of younger children with coloring books other more juvenile activities. In order to appeal to and serve adolescents and young adults, programs should consider offering and advertising adolescent-specific content. The unique life transitions that take place during adolescence, and the differentiated aspects of psychosocial, spiritual, and mental health care that adolescents may

need (as compared to younger children) should be considered in order to tailor and advertise interventions to patients and their families.

Streetlight at UF Health Shands is a 1:1 peer support program that enhances the QoL of chronically ill adolescents and young adults by offering opportunities for coping, providing opportunities to tend to their psychosocial health, and improving their mental health status. This program, and others that similarly address these predictors of QoL, would be important to further study for potential replication at other hospitals. Two additional 1:1 peer support programs in this sample, the Emerging Pediatric Professionals program at Wolfson Children's and Carolina Pediatric Attention Love and Support at University of North Carolina Children's Hospital should be studied more closely, perhaps comparing patients' perspectives across programs to illuminate commonalities and differences. These two programs span various age groups and diagnoses, offering additional important factors for consideration.

Given the limited literature on the benefits of 1:1 peer support versus fostering general friendships with others (i.e., in the neighborhood, at school), further examination these two domains would be particularly useful. One-on-one peer support provides an outlet for chronically ill adolescents to confide in a similarly-aged peer about their illness (sometimes a shared illness), its impact on their life, and other relevant circumstances for which a peer could understand and/or empathize.(22) Spending time with a friend may also be beneficial, though not all friends may understand or empathize in the same way as a designated peer support person. Understanding the differences and overlaps in these supports as it relates to QoL or HRQoL would be beneficial.

Other inpatient program offerings, including those widely adopted (i.e., Child Life therapy, music therapy, pet therapy, art therapy, pastoral care/spiritual support, and dedicated

activity rooms for teens) and those less widely adopted (i.e., integrated psychosocial clinical care teams, family-to-family mentorship programs, music studios or radio stations in the hospital, and hospital school programs) should be examined for their potential to address key predictors of QoL and HRQoL among chronically ill adolescents as well. When possible, hospitals might explore opportunities for integration of inpatient services with services provided through a patient-centered medical home.

3.8 Tables and Figures

Table 3.1 Summary of Inpatient Programs Formally Offered to Chronically Ill Adolescents at 11 Children's Hospitals in the Southeast U.S., Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

	Child Life Therapy	Pet Therapy	Art Therapy	Music Therapy	General Hospital Volunteer Program	Pastoral Care/ Spiritual Support	Dedicated Activity Room(s) for Teens	Hospital School Program	Integrated Psychosocial Clinical Care Team	Media Studio/ Radio Station	Family-to-Family Mentorship Program	1:1 Peer Support Volunteer Program
Children's of Alabama*†	■	■	■	■	■	■	■	■	■			
Wolfson's Children's*	■	■	■	■	■	■	■			■		■
UF Health Shands†	■	■	■	■	■	■	■	■	■			■
Children's of Atlanta*	■	■	■	■	■	■	■	■	■	■	■	
Duke Children's*†	■	■	■	■	■	■		■				
Levine Children's*	■	■	■	■	■	■	■	■		■	■	
UNC Children's*†	■	■	■	■	■	■	■	■	■			■
MUSC Children's*†	■	■	■	■	■	■	■					
St. Jude Children's*	■	■	■	■	■	■	■	■			■	
Vanderbilt Children's*†	■	■	■	■	■	■	■	■	■	■		
Hopkins Children's†	■	■	■	■	■	■	■			■		

*dedicated children's hospital † academic medical center Note: blue shading denotes program provided

Table 3.2 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Children's of Alabama, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	**Program Name and Description**(21,28)
Child Life Therapy	Child Life – "The Child Life Program at Children's of Alabama recognizes that illness and hospitalization are stressful events in the lives of children and their families. By using age appropriate education, preparation and supportive activities, we strive to minimize that stress and help children and their families cope positively with their healthcare experience. Child Life Specialists are part of the health care team. They are professionally trained in understanding and meeting the unique needs of children and teens in the healthcare environment."
Pet Therapy	Hand in Paw – "Most of Hand-in-Paw's services and programs focus on children and youth. We provide programs for children and youth at-risk using a specific curriculum to teach positive life skills and modify behavior. In health care facilities, we work with staff to provide emotional and physical rehabilitation with specific goal-oriented interactions between patients and therapy animals."
Art Therapy	Clowns at Children's – "Clowning is serious business at Children's. Who else can turn a frown upside down? We have professionally trained clowns who are members of the Big Top Alley. No, you just don't put on makeup and come in; you must graduate from clown school. We often have requests for clown visits from patients and families. Clowns make rounds several days and evenings each week. Their role is to have fun and bring a smile to all they meet, even to those who may have a little fear. Our clowns are sensitive to you as well. There is nothing like playing bingo when the clowns are in charge. And there are tricks to see and learn, and most importantly the patients will probably get a sticker and definitely a smile like they have never seen before."
Music Therapy	Soundscapes for Children's – "Soundscapes for Children's (Soundscapes) is a year-round music program designed to help create a quiet, soothing, and calm atmosphere. With this program, talented local musicians – individuals or small groups – have an opportunity to play soft background music as patients, family members, guests, and Children's of Alabama employees go about their day. Our hope is that this ambiance will help patients in their recovery, as well as families in stressful times."
Integrated Psycho-social Clinical Care Team	Hope and Cope Psychosocial Program (Hematology-Oncology only) – "…provides support and services from diagnosis onwards using a family-centered approach, where the family and healthcare providers are partners working together to best meet the needs of the patient. Our interdisciplinary team of skilled and compassionate specialists, including social workers, child life specialists, pediatric psychologists, pediatric neuropsychologists, chaplains, hospital-based teachers, school liaisons, art, music, and rhythm therapists provide emotional, psychological, and spiritual support, and also assist with concrete needs."
General Hospital Volunteer Program	Patient Pals – "…volunteers trained by Child Services to engage children in constructive diversionary activities. They may provide other supportive services such as providing respite for parents and stocking/distributing literature."

General Hospital Volunteer Program	Teen Volunteers – "You are considered a teen volunteer if you are still enrolled in high school, or have just graduated but not yet started college. Our program is a unique way for high school students to learn more about the healthcare environment, while helping the patients, families, and guests we serve. In many cases, volunteers will be asked to involve the patient in educational activities or play a game. Other duties might include escorting a family to a location on the campus, helping restock supplies, checking in on a patient to see if he/she needs anything, or assisting families in the family center on each floor. We use a lot of coloring sheets and crayons around here, but you don't have to be an artist…just a pal willing to help out."
General Hospital Volunteer Program	College Volunteers – "You are considered a college student if you are taking one course for fun or working towards a degree, regardless of your age. You must also be a high school graduate or have a GED. What an exciting opportunity we have to offer our college volunteers! Our program is one that is sure to give you a deep, personal satisfaction by helping others. We know there may be many demands on your time, but we certainly hope you will consider us when you are choosing a place to volunteer. Please know your smile, kind words, or helpful action can make all the difference to someone who is having a challenging day while in the hospital. Our ongoing program that is 48 hours over 16 weeks does intake every month of the year except December."
General Hospital Volunteer Program	Adult Volunteers – "Are you interested in finding a rewarding way to give back? As an adult volunteer there are endless possibilities to do so. A few options include doing clerical work; greeting our patients, their families and guests while assisting them in getting to their destinations; and sitting with patients for their parents to get out of the room for a short while. Most volunteers are assigned a three-hour timeframe one day a week. You are in your same assignment each week. Also the majority of our assignments are during the weekday. However we do have limited opportunities during the evenings and on weekends."
Pastoral Care/ Spiritual Support	Pastoral Care – "Our clinically trained and certified chaplains assist patients and their caregivers by bringing awareness to the spiritual resources that are available to them during their hospital stay. Pastoral Care Services provided by Children's of Alabama chaplains include: Bedside visits with patients and families, Serving as a liaison between the medical team and family during trauma and crisis situation, Providing sacred rituals and spiritual resources such as sacraments, prayer, sacred texts, meditation or Godly Play, Leading weekly worship services in Bew White Chapel, Facilitating contact with community, spiritual care representatives and resources. The Pastoral Care Team is available around the clock.
Dedicated Activity Room(s) for Teens	Teen Room – "Familiar and fun activities can help children feel less anxious about their fears and concerns related to unfamiliar surroundings, people and events. Our inpatient activity rooms provide toys, games, art, books, movies and music to help children feel more comfortable while in the hospital. We offer age-appropriate activity rooms including an infant/toddler room, a school-age room, and a teen room."
Hospital School Program	Sunshine School Program – "School plays a significant role in every child or adolescent's life. When a child is hospitalized, it interrupts normal routine. The Sunshine School supports that needed normalization by providing structure and distraction of illness. Our program shows children and adolescents that they can expect to return to normal events and have opportunities to be creative and productive while maintaining a sense of identity and hope during hospitalization."

Table 3.3 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Wolfson Children's Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	**Program Name and Description**(10,29)
Child Life Therapy	Child Life – "Child Life specialists at Wolfson Children's help kids understand what's happening and can ease fears through education, support and play. Our Child Life specialists are essential members of your child's health care team. By easing stress and anxiety, they help kids gain a sense of control in the hospital environment. How we help: Reduce pain and anxiety during procedures through distraction and coping, Explain procedures and treatments in a way your child will understand, offer activities to promote self-expression and coping and help make the hospital feel more friendly and comfortable, ensure kids with autism or developmental delays have sensory toys and coping plans to meet their needs"
Child Life Therapy	Once Upon a Room – for patients who are inpatient for 2+ weeks; "this Los Angeles-based non-profit reimagines the hospital rooms of children seeking active medical treatment, and brings joy to everyone involved."
Pet Therapy	Pet Therapy – "Eagerly awaiting the wagging tails that come bouncing down the hospital halls on their scheduled days, it's not surprising that the patients, families and staff become attached to the special dogs in the pet therapy program. But pet therapy does more than elicit giggles. Dogs provide a therapeutic value to hospitalized children beyond what their human family members and our hospital team can."
Pet Therapy	Comforting Paws – "Our Comforting Paws dog visitation program lets long-term patients visit with their family pet in a special room at the hospital. It's for kids who have been in the hospital 5+ days or in an end-of-life situation."
Art Therapy	Art Therapy – "Art with a Heart in Healthcare works with the Child Life team to give children who are hospitalized an opportunity to express themselves through various artistic mediums. Painting, drawing, music, storytelling and photography gives patients the opportunity to discover their own artistic talents and learn about the arts. Together, artists and patients create art that reclaims the child's sense of self, making a powerful contribution to the healing process. A majority of the kids we meet have their first art experience with us."
Music Therapy	Music Therapy – "Music has therapeutic benefits – from lowering stress and blood pressure to easing pain. Our music therapist customizes each session according to diagnosis, age and musical preference to create opportunities for patients to improve comfort and coping."
General Hospital Volunteer Program	Hospital Volunteers – "Our volunteers donate time to a variety of programs and departments at the hospital, and work in a variety of roles ranging from patient and family support to clerical work. We're looking for people who are willing to help with whatever is needed."
1:1 Peer Support Volunteer Program	Emerging Pediatric Professionals – Nursing students at University of North Florida are given the opportunity to partner with patients over the course of a semester. They are supervised by Child Life, and provide socialization at the bedside. Student are selected through a rigorous application process.

Pastoral Care/ Spiritual Support	Spiritual Care – “Our pediatric chaplains minister from a multi-faith perspective and are culturally sensitive to all people, regardless of religion, creed, race, gender, nationality or beliefs. Pediatric chaplains are assigned to every unit in the children’s hospital and routinely make rounds, just like other medical professionals. The children’s chapel is a place where people of all faiths, cultures and ages are welcome for spiritual renewal. This sanctuary offers personal reflection and is designed for comfort and peace.”
Media Studio/ Radio Station	Walmart Sam’s Club Media Center – “Entertainment, such as magic shows, musical performances and more, are a welcome distraction to patients and families undergoing treatment. Performances take place in our Walmart Sam’s Club Media Center, allowing them to be broadcast into patient rooms for those who can’t attend.”
Dedicated Activity Room(s) for Teens	Teen Room – A teen-only space with activities such as pinball, foosball, various video game systems, and more. Halloween parties are also hosted in this space.

Table 3.4 Inpatient Programs Formally Offered to Chronically Ill Adolescents at UF Health Shands Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	**Program Name and Description**(18,30)
Child Life Therapy	Child Life – "Child Life Specialists at UF Health Shands Children's Hospital are certified professionals who work in partnership with families, doctors, nurses, and other caregivers to meet the unique emotional and developmental needs of children and families. Child Life Specialists at UF Health Shands Children's Hospital: Provide age-appropriate play and activities to promote coping, expression of feelings, and adjustment to the healthcare setting; Prepare, educate, and support children undergoing medical procedures and treatments to help them understand what to expect, clear up any misconceptions, and build healthy coping skills; Provide support and distraction for patients during medical procedures; Provide non-threatening, age-appropriate explanations and preparations; Help children understand diagnosis or illness; Promote normal growth and development; Offer legacy building and memory making to help children cope with grief; Develop supportive relationships with patients and families and promote family centered care"
Pet Therapy	Pet Therapy – "Behind each volunteer (human and canine) and every single volunteer hour, there is a story. All of our pet therapy volunteers have great love for animals and a great desire to help our patients."
Pet Therapy	Personal Pet Visitation – "At UF Health we understand that pets are an important part of our lives and our healing. For our long-term patients we provide an opportunity to include personal pet visitations with dogs as part of the hospital stay because we know that sometimes a visit from our favorite dog is just what the doctor ordered. Personal pet visitation allows for the patient's own dog to visit him/her in the hospital, while making sure we maintain the health of our pet therapy volunteers and our patients."
Art Therapy Music Therapy	Arts in Medicine – "From humble beginnings, UF Health Shands Arts in Medicine has grown into one of the largest comprehensive arts in healthcare programs in existence. Starting with two volunteer visual artists working on the Bone Marrow Transplant Unit, Arts in Medicine now has 16 paid artists in all art disciplines working in six separate buildings throughout the UF Health system, covering the Gainesville and Jacksonville communities. Our programs are designed to transform the hospital experience for patients, visitors, caregivers and staff. We focus on the following areas: the visual arts, the literary arts, the performing arts, and design and aesthetics."
Integrated Psychosocial Clinical Care Team (disease-specific)	Adolescent and Young Adult (AYA) Cancer Program – "The UF Health AYA Cancer Program addresses the compelling and unique medical and psychosocial needs of our adolescent and young adult patients — from diagnosis to survivorship. This includes needs such as fertility preservation counseling, age-appropriate distress screening, psychosocial support, career/vocational resources, family-building options in survivorship, increasing access to clinical trial participation and multidisciplinary care. With this support, the UF Health AYA Cancer Program hopes to help break down the barriers to effective treatment commonly experienced by this distinct population, giving each person the best chance at beating his or her disease."
General Hospital	Degree-Seeking and Non-Degree Seeking Hospital Volunteer Program – "Degree-Seeking volunteers are asked to commit to one full semester for a three hour shift once a week. Student volunteers are allowed two absences during each semester. Those who have more than two absences during

Volunteer Program	a semester must make up any additional absences. Non-Degree Seeking volunteers are asked for a six month commitment for a three hour shift once a week."
General Hospital Volunteer Program	VolunTEEN Program – "Hospital volunteer program for 14-17 year-old students"
1:1 Peer Support Volunteer Program	Streetlight – "The UF Health Shands Streetlight Program is a free adolescent and young adult support program for people, ages 13-25, living with cancer, cystic fibrosis, sickle cell anemia, organ diseases and other chronic or life-limiting illnesses. Streetlight seeks to: provide consistent psychosocial support and opportunities for peer socialization for adolescent and young adult palliative care patients throughout hospitalizations; adequately educate and support volunteers in their role in providing psychosocial support in healthcare; empower the coping skills and psychosocial resilience for program volunteers and adolescent and young adult palliative care patients; provide adequate emotional support and training to volunteers to help process the emotional intensities they may experience throughout Streetlight involvement; provide ongoing emotional bereavement support to patients and families of deceased patients; and to evaluate, research, and improve Streetlight program components to investigate and optimize the role of social support in improving health outcomes for frequently hospitalized adolescents and young adults."
Pastoral Care/ Spiritual Support	Pastoral Services – "The pastoral services staff at UF Health seeks to provide spiritual support for patients and their family members by providing spiritual counseling, participation in consultations, sharing sacraments and other rituals of faith and being available as supportive personas who can listen objectively to the concerns voiced to them."
Dedicated Activity Room(s) for Teens	Teen Lounge: Streetlight facilitates Teen Lounge weekday evenings from 6:30-7:30pm in the Playroom. At 6:30pm, Streetlight reserves the room for pediatric patients 13 years-old and older, engaging patients in age appropriate activities like playing video games pool, performing karaoke, making art, playing and performing music, and painting nails. Teen Lounge is an opportunity for teen and young adult patients to leave their rooms and socialize with patients and volunteers who are their age.
Hospital School Program	Hospital Homebound – "Michelle Roberts has been a Homebound Instructor with Alachua County Schools since February 2016. She came to Shands following her work as a Learning Specialist with the University of Florida's Athletic Department, where she had worked with collegiate athletes since 2008. She can see patients during admission or as outpatients when relocated to the local area for an extended period of time."

Table 3.5 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Children's Healthcare of Atlanta, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(9,31)
Child Life Therapy	Child Life – "Child Life specialists help our patients cope with hospital life and their illnesses by giving them chances to play and interact in our activity centers. All three Children's locations feature activity centers supplied with toys, games and crafts for all ages.
Pet Therapy	Children's Canines for Kids – "Children's Canines For Kids animal assisted therapy program helps ease anxiety and promotes shorter recovery times. Canine Assistants trains our service dogs to provide therapy, hope and healing by doing everything from giving loving support during chemotherapy treatments to offering comforting snuggles before surgery. Children's also partners with outside service animal companies who often visit our hospitals. Patients are notified when we have these furry visitors so that they may interact with them if they choose to."
Art Therapy	Art Therapy – Patients are offered the opportunity to work with an artist in residence to do art in their room or in a common area of the hospital.
Music Therapy	Music Therapy – Available to patients in certain units only by artists in residence. Periodically, outside musicians perform concerts in the lobby or small-scale music lessons, teaching patients who wish to learn how to play instruments and write music.
Integrated Psychosocial Clinical Care Team (disease-specific)	Pediatric Advanced Care Team (PACT) – "Our PACT is trained to listen, assess and find innovative ways to make life as good as possible for each child. We help children and families manage physical symptoms, Psycho-social challenges, Spiritual challenges, Family support, Team support, and Community support." This team functions as a palliative care team.
General Hospital Volunteer Program	VolunTEEN – "The VolunTEEN program is for high school students ages 15 to 18 who are looking for a rewarding way to spend a portion of their summer. VolunTEENs will spend their days bringing smiles and laughter to the halls of the hospital. From the front desks to the patient units, VolunTEENs will craft, play games and most importantly leave a lasting impression on our patients and families."
General Hospital Volunteer Program	College Volunteers - "The Children's College Volunteer program is for college students looking for a way to help patients, families and staff. The 12-week program is offered during the fall and spring semesters. The program is not offered during the summer. Students must be able to commit to a weekly three-hour shift."
Pastoral Care/	Chaplain support – "Our chaplains are trained to respond to the spiritual needs of patients in the hospital setting. They provide spiritual support and guidance to patients and families as they seek healing, meaning and hope in the face of illness or injury."

Spiritual Support	
Family-to-Family Mentorship Program	Family Mentor Program – "The Family Mentor Program matches families facing new or challenging medical experiences with trained, veteran parents. Mentors share information and coping skills to help families reduce stress and manage their child's healthcare in a positive way. They're trained to provide support, modeling, suggestions and validation to families."
Media Studio/ Radio Station	Seacrest Studios – "While our patients at Children's are living inside hospital walls, they're still curious about the outside world, and they want to stay connected to it. That's why the Ryan Seacrest Foundation has its first-in-the-nation broadcast media center at Egleston. Seacrest Studios Atlanta teaches our kids about the exciting world of radio and TV broadcasting during their stay at Children's. Seacrest Studios Atlanta is on the air every Tuesday, Wednesday and Thursday, from 2 p.m. to 6 p.m. in the lobby at Egleston. Patients in Egleston can come to the studio at those times to learn about radio, introduce songs over the air, record greetings and play games with other patients or interns at Seacrest Studios Atlanta. Some patients have even returned there to perform during a broadcast."
Dedicated Activity Room(s) for Teens	Teen Rooms – "Hematology/Oncology has a teen room at each campus, a Microsoft Teen Room at the Scottish Rite campus, and the Library at Egleston campus has a dedicated teen space. All teens spaces are limited to teens and include technology, comfortable setting, and privacy!"
Hospital School Program	Hospital Homebound – "Hospital homebound (HHB) services are designed to provide continuity of educational services between the classroom and home or hospital for students in Georgia public schools whose medical needs, either physical or psychiatric, do not allow them to attend school for a limited period of time."

Table 3.6 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Duke Children's Hospital & Health Center, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(11,32)
Child Life Therapy	Child and Adolescent Life Program – "The Duke Children's Child and Adolescent Life Program provides a great opportunity for volunteers to work directly with children and the Child and Adolescent Life team to provide supervision and play for children in the inpatient playrooms. Using games, puzzles, art, and other imaginative and appropriate play, volunteers give pediatric patients the opportunity to enjoy different activities while making the hospital experience less stressful. Experienced volunteers may also work at bedside to help a child enjoy quieter activities - such as reading a story, painting fingernails or assembling a puzzle."
Pet Therapy	Pets at Duke (only available to pediatric oncology, pediatric intensive care unit, and pediatric cardiac intensive care units) – "The Pets at Duke program, offered through the Duke Cancer Patient Support Program, offers many benefits to our patients. Research shows that animal-assisted therapy, or pet therapy, is an effective form of psychotherapy intervention that reduces stress and depression. It also provides a sense of companionship that can combat feelings of isolation. The relaxation and feelings of connection that people feel with an animal -- in this case a dog -- facilitate healing and rehabilitation."
Art Therapy Music Therapy	Arts & Health at Duke – "Arts & Health provides literary, performing and visual arts programming to Duke University Hospital patients and those who care for them. Since 1978, Arts & Health has sought to enrich and support the healthcare environment by providing quality literary, performing and visual arts programming to Duke University Hospital and its hospital-based clinics. We believe that access to the arts is essential to the health and well-being of patients, their loved ones, staff, volunteers and visitors. Arts & Health provides a multitude of services for patients and those who care for them, including journaling sessions, musical performances and art for waiting areas and patient rooms."
General Hospital Volunteer Program	College student volunteer program – "Although the program is designed to meet core competencies for students considering a career in health professions, volunteering is open to all majors. Volunteer programs at Duke University Hospital do not provide clinical or shadowing experience. They do, however, provide opportunities for patient and family engagement with a hospital or clinic setting."
General Hospital Volunteer Program	Junior volunteers – "The Junior Volunteer program allows high school students (ages 16-17) to volunteer at Duke University Hospital. Maturity, compassion, and commitment to serve others are some of the characteristics we seek in our high school volunteer program. As junior volunteers assist and engage with our patients and visitors, they learn valuable lessons that they will use throughout their adult lives. This program is only offered during the summer months."
Pastoral Care/ Spiritual Support	Chaplain Services and Education – "Chaplain services are available at all Duke Health hospitals any time of day or night. We provide support, guidance, and someone to listen when you or a loved one is in need. Whether you're facing a sudden health challenge or end-of-life decisions, need guidance on ethical decision-making, or need a place to focus on prayer and meditation, we're here for you."

Hospital School Program	Hospital School – “The Hospital School is operated by Durham Public Schools and staffed with North Carolina certified teachers. Annually, the school serves around 300 students (both inpatient and outpatient) from preschool through high school. The Hospital School is a great patient benefit and enables students to continue their academic development and studies while undergoing medical treatment. Services provided for the students include academic assessment, direct instruction and transition support for returning to their permanent school. Hospital teachers work with classroom teachers to coordinate the curriculum standards and specific skills development. Students receive credit for work completed and school attendance during hospitalization. The teachers serve as an instructional resource for students while they are away from the traditional school environment. When students end a grading period in the hospital, the hospital teachers submit a report card reflecting grades earned and send the information to the traditional school. Students' cumulative records remain at the permanent school of record.”

Table 3.7 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Levine Children's Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(23,33)
Child Life Therapy	Child Life – "Our Child Life specialists at Levine Children's Hospital work alongside doctors, nurses and families to help children cope while being in the hospital – and adding in a little bit of fun, whenever possible. We are trained to provide social and emotional support for hospitalized children, helping explain hospital procedures and treatments in ways they can understand. We use medical play, videos and other distractions to make a child's experience feel safer and more normal, while restoring their sense of control.
Pet Therapy	Pet Therapy – "For a child in the hospital – especially one who has a beloved pet at home – interaction with a certified pet therapy dog goes beyond medicine. The pet therapy program at Levine Children's Hospital is designed to provide its young patients with that needed distraction and a little bit of happiness in what is typically a scary time. All dogs in the program are licensed and registered with Pet Therapy International Incorporated, and are always accompanied by their licensed handlers who supervise all patient interactions to ensure safety."
Art Therapy	Arts for Life – "Arts For Life is dedicated to supporting pediatric patients and their families. By providing educational art programs, we enrich patients' lives, nurture their minds and spirits, and encourage positive healthcare experiences for children and their families. We bring dynamic, educational arts lessons to young patients and families at Levine Children's Hospital. Our visual art, creative writing, and music programs decrease patient stress and anxiety, keep patients active and engaged, and help families cope with the realities of illness."
Music Therapy	Music Therapy – "Everyone knows that music has healing properties. It can perk you up when you're feeling low or soothe you when you're anxious. At Levine Children's Hospital, we use music therapy as part of the overall healing process. Our board-certified music therapist uses several therapies with patients and their families. Older kids can participate in lyric analysis and talking about the meanings of songs, while smaller kids are often calmed by hearing a familiar song from home. From pure distraction to pain management, music can make almost any situation better."
General Hospital Volunteer Program	In-House Volunteers – "Our in-house volunteers work within Levine Children's Hospital, committing to a regular schedule for a one-year time period. In-house volunteers can provide support in a variety of positions: Assisting Child Life in making a child's stay more enjoyable by reading stories, playing games or coloring with children and their siblings, Providing non-clinical support to infants and toddlers in the progressive care nursery, Performing general office assistance such as answering phones, paging staff, making copies or filing, Greeting patients, family and visitors, Assisting in the transport and discharge of patients, Assisting families and patients in the Family Resource Center, Delivering flowers and magazines to patients and families, Assisting in waiting rooms of the emergency department, radiology and surgery, Reading stories, playing games or coloring with patients and their siblings in the pediatric hematology / oncology clinic and the pediatric rehabilitation unit
General Hospital Volunteer Program	Teen Volunteers – "Teen volunteers provide non-clinical support throughout the hospital, such as delivering equipment to units, providing directions or escorting patients or visitors. The department of volunteer services looks for mature, self-driven, dependable teens who are seeking to serve the patients, families and staff members of Levine Children's Hospital. The ideal candidate is a volunteer who is interested in learning more about the healthcare field. Educational learning sessions give students the opportunity to connect with healthcare professionals and explore

	a broad variety of hospital specialties. By combining hands-on experience through volunteer work and education, the program fosters interests of the healthcare leaders of tomorrow, while serving the community of today."
General Hospital Volunteer Program	Patient Experience Ambassadors – "Our patients deserve to have an outstanding experience at Levine Children's Hospital. Patient Experience Ambassadors help make sure that happens by working with our nursing units, visiting patients to ensure every patient is receiving the best care possible."
Pastoral Care/ Spiritual Support	Chaplain and Spiritual Care – "Sometimes our spirits need healing as much as our bodies. In a hospital setting, the person providing spiritual and emotional care is called a chaplain. At Levine Children's Hospital, we have our own chaplains who specialize in the care of children. Chaplains are here for you 24 hours a day to listen and provide other clinically relevant spiritual and emotional care."
Family-to-Family Mentorship Program	Momcology Group – This group supports moms and families of adolescents new diagnosed with cancer. The group's coordinator pairs families who can provide mutual support while navigating this difficult illness with their teen.
Media Studio/ Radio Station	Seacrest Studios – "The 652-square-foot studio, located inside the hospital's Overcash Atrium, includes five guest microphones, production-quality video cameras and radio equipment, and a green screen that allows patients to participate in video projects. The studio has a full-time program director and programming that includes game shows, celebrity interviews and performances. Our patients can stop by the studio to participate live. Or, they can view programs in their room, even having the ability to request songs or ask questions of the people being interviewed."
Dedicated Activity Room(s) for Teens	Teen Room – "Teens and their siblings, 13 years and older, are welcome to visit the teen room, located on the 11th floor. This room is equipped with video games, a computer, a foosball table, a pinball machine and board games."
Hospital School Program	Hospital School Program – "When a child is in the hospital, the most important thing for them to concentrate on is feeling better. Here at Levine Children's Hospital, we also understand the importance of education. We keep our patients on track with their schooling, so when they leave the hospital, they can jump back into class with their peers. Our Hospital School Program provides educational support to preschool children with disabilities and direct instruction for students in kindergarten through 12th grade. Lessons are based around the Common Core State Standards and your child's assignments from his or her home school. We have a high-tech classroom for patients or siblings, and a teacher who visits with patients Monday through Friday. You don't want your child to fall behind and we don't either."

Table 3.8 Inpatient Programs Formally Offered to Chronically Ill Adolescents at North Carolina Children's Hospital at University of North Carolina, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(34,35)
Child Life Therapy	Child Life – "Our team of child life specialists at UNC work with patients and families to improve their overall health care experience. Using appropriate teaching tools, we help prepare children and their families for upcoming health care experiences and life-altering events. We build relationships with our patients and their families, and provide support based on individual needs. We use evidence-based interventions including therapeutic play, psychological preparation for procedures and coaching through medical experiences."
Pet Therapy	Pet Therapy – Offered to provide patients distraction and comfort in the inpatient setting.
Art Therapy	Art Therapy – Offered to provide patients the opportunity for creative expression, alongside artists in residence.
Music Therapy	The Charles Goren Music Room – "The Music Room affords N.C. Children's Hospital patients and their families an opportunity to express themselves or continue their interest in playing musical instruments while in the hospital. The Music Room is supervised by Recreational Therapy and Child Life. It is located off of the Play Atrium on the seventh floor of N.C. Children's Hospital. The equipment in this room also aids in the healing process by allowing self-expression. With the supervision of a full-time Senior Child Life Specialist and a part-time music therapist, children can create music CDs or individualized relaxation, hypnosis, story or guided imagery tapes to assist in the management of pain, stress or anxiety."
Integrated Psychosocial Clinical Care Team (disease-specific)	Aftercare Coordinator Program – These programs are specific to burn patients, those with a chronic illness, hematology/oncology. They serve a supportive role in connecting families to build shared experiences. Introduction to these programs begins in the inpatient setting, and continues after patients are discharged. The program provides opportunities for adolescents to meet peers with similar diagnoses. Teen support groups are facilitated through this program in the outpatient setting.
General Hospital Volunteer Program	Adult Volunteers – "Each volunteer member assists in providing excellent care and understanding by taking the time to give patients and their families the extra help they need during their hospital stay. Give back to your community and donate your time, care and support and apply to our volunteer program today. Applicants must be able to commit to volunteering on a weekly basis for 2-3 hours each week and to a minimum of 6 months AND 40 hours of volunteering. "
General Hospital Volunteer Program	Undergraduate Volunteers – "Volunteer Services at UNC Medical Center in Chapel Hill is proud to work with over a 1,000 undergraduate students each year who devote their time to helping our patients, families, and staff. Our goal is to offer meaningful and educational opportunities for college students while meeting the needs of our clinical departments. Volunteer placements are available for undergraduates throughout all of the Medical Center campus hospitals. Applicants must be able to maintain a regular schedule consisting of at least one 2-3 hour shift per week. Undergraduate volunteers commit to a minimum of 2 Semesters AND 50 hours of volunteering (25 Hours each semester)."

1:1 Peer Support Volunteer Program	Caroline Pediatric Affection Love Support Program (CPALs) – Hematology/Oncology only – UNC ungraduated students can volunteer to be paired with an adolescent patient. They often follow them through their treatment, attending appointments with them and visiting them in the inpatient setting. The volunteers receive extensive training. Many of them are planning to enter into health professions. Often, the volunteers also establish supportive relationships with the parents/caregivers.
Pastoral Care/ Spiritual Support	Pastoral Care/Spiritual Support – "The Pediatric Palliative Care Service consists of the Children's Supportive Care Team and the NC Children's Hospital Pediatric Palliative Care Committee. Palliative care for children is focused on relieving suffering and improving quality of life. The Children's Supportive Care Team is designed to aid children with serious illness and their families with the following: Pain and symptom management, Complex decision-making, Parent and sibling support, End of life planning, Bereavement care for families
Dedicated Activity Room(s) for Teens	Jason Clark Teen Lounge and Game Room – "The Jason Clark Teen Lounge and Game Room is supervised by Recreational Therapy and Child Life. This seventh floor recreational area was renovated in 2013 to include updated furniture and technology. The room has one section dedicated as a lounge and a separate area for arcade style games."
Hospital School Program	Hospital School – "The UNC Hospital School, a part of Chapel Hill-Carrboro City Schools, was North Carolina's first accredited pre-kindergarten through 12th grade (PK-12) hospital school and has grown from a staff of two serving approximately 50 patients annually to a staff of 16 serving more than 2,000 students each year. Hospital School teachers and support staff will collaborate with your child's local school and teachers to help him or her keep up with their studies during hospital stays and provide a smooth transition back to school."

Table 3.9 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Medical University of South Carolina Children's Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(36,37)
Child Life Therapy	Child Life – "The child life staff have specialized training and experience in understanding children's reactions to illness and hospitalization. Our team is staffed by professionals who hold degrees in child life, child development, education, and related fields. As part of the MUSC Children's Health team, the staff members utilize their skills to support and promote the developmental progress and emotional well-being of children.
Pet Therapy	Pet Therapy Program – "The Center for Disease Control and Prevention most recently published that pets "provide invaluable health benefits to their human companions." Pets can lower your blood pressure, cholesterol levels, triglyceride levels, pain levels, and the feeling of loneliness. They are an excellent companion for our patients and their families when they are here."
Art Therapy Music Therapy	Arts in Healing – "Arts in Healing is changing what's possible in health care by providing access to the inherent healing powers of the arts to improve the health and well-being of the community. From art installations to bedside therapeutic interventions, our diverse programming aims to enhance the lives of patients, families, visitors and staff." Services offered include music and visual arts therapy, in addition to performing arts.
General Hospital Volunteer Program	Courtesy Cart – "The Courtesy Cart goes door to door offering coffee, tea, and hot chocolate to parents in the hospital. This placement is available in two-hour shifts every morning."
General Hospital Volunteer Program	Happy Wheels – "This cart carries new books and toys to all of the children in the hospital each week. Each child is given the opportunity to "shop" for that something special on the cart that will hopefully make their stay more tolerable. The children look forward each week to the Happy Wheels cart coming around and stopping by their room. Volunteers are rewarded by bright smiles, and happy faces as the children choose their gift. No one wants to miss out on the Happy Wheels cart."
General Hospital Volunteer Program	Unit-Based Volunteers – "Unit-based volunteers are placed on inpatient units to support staff to interact with children as well as support the clinical staff with responsibilities, such as: Providing companionship to patients and their families, Sitting with patients when parents are unable to be there, "Rounding" on families to assure comfort needs are being met, assisting with discharges, assisting staff with phones and call bells"
General Hospital Volunteer Program	Candy Striper Program – "The goal is to provide positive, energetic students (ages 14 to 18) who are possibly interested in health care or other real world experience with an environment and an opportunity to learn, help others, build friendships, and give back. The program also provides assistance to departments that could use extra sets of hands. The Candy Striper Volunteers also help to make the hospital a little happier and friendlier."
Pastoral Care/ Spiritual Support	Chaplain – "assists patients and families needing spiritual help or supportive counseling. He or she will listen to what is important to you and your family and show respect toward differences in cultures, beliefs, and lifestyles."

Dedicated Activity Room(s) for Teens	Teen Space within the Jerry and Anita Zucker Family Atrium – “The Atrium is designed to meet the play and activity needs of children, teens, and their families during hospitalization. We recognize that a hospital stay can be stressful and upsetting. The opportunity to play is normal, familiar, and comforting. Play and activities can assist children and families to cope positively with the hospital experience. The Atrium is designated as a “safe place” where medical treatment and procedures do not take place. Doctors, nurses, and other medical staff are encouraged to play with their patients in this area.” Within the atrium, there is a dedicated teen space, with video games and other age-appropriate amenities – just for teens.

Table 3.10 Inpatient Programs Formally Offered to Chronically Ill Adolescents at St. Jude Children's Research Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(38)
Child Life Therapy	Child Life – "Nineteen full-time child life specialists work at St. Jude Children's Research Hospital. Their goal is to help children cope with the challenges of health care and hospitalization. These services are offered to all families in all clinical areas. Our child life specialists work closely with children and teens to provide age-appropriate explanations and preparations. The activities help patients and siblings better understand what is happening. Such interactions also build trust so that they know what to expect during this time of change. Child life specialists create many opportunities for children to play and express themselves. These therapeutic activities promote patients' and siblings' development and enhance their coping skills. The activities also provide an outlet for feelings, peer interaction and a sense of mastery."
Pet Therapy	Paws at Play Hospital Dog Program – "These four-legged friends offer patients social contact, reduce stress, and stimulate senses through animal-assisted therapy. Some children at St. Jude may be anxious about treatment. Puggle and Huckleberry work with their humans in Child Life to help patients cope with receiving treatment and being in the hospital. The Paws at Play program aims to distract patients from their illness, symptoms, pain and anxiety. Our trained service dogs will offer unconditional love and acceptance. They will also motivate and support patients through social interaction."
Art Therapy	Art Therapy – "Art therapy is facilitated by a professional art therapist. Providers who specialize in art therapy have training in art, child development, and psychology. An art therapist provides a safe, creative environment for children and teens to express themselves in group or one-on-one settings. An art therapist may recommend specific techniques such as painting or sculpting, or the therapist may allow patients to choose the method that they would like to use. Art therapists are trained to recognize symbols and metaphors often expressed through the creative process. Art therapy can improve communication and connections among family members by providing a shared activity. In some cases, families may use art therapy activities to make memories and keepsakes during end-of-life care."
Music Therapy	Music Therapy – "Our Music Therapy program is part of the Child Life Department. Music therapy can be beneficial for reducing both anxiety and pain perception and can provide your child with a healthy outlet to express their emotions. Any patient can be referred to one of our highly trained and certified music therapists by either a member of the patient's treatment team, a family member or by the patient themselves."
General Hospital Volunteer Program	Volunteen Program – "The Volunteen program strives to provide a rich well-rounded experience of service. It offers the opportunity to develop team building as well as leadership skills and fosters self-awareness. The program is highly demanding, as each teen works closely with patients, siblings and parents. Volunteens are able to explore possible career paths as well as gain an understanding of how our unique facility has completely changed how the world treats children with cancer and other catastrophic diseases. The Volunteen Program is a two-week program offered two different times during the summer. Each session consists of approximately 16 new Volunteens and five returning Volunteens who serve as program assistants in a leadership role."
General Hospital	Summer Volunteer Program – "The Summer Volunteer Program is highly structured to accommodate individuals who wish to gain experience with patients in a hospital environment. Several volunteer opportunities have been identified to provide a unique St. Jude volunteer contribution,

Volunteer Program	thus helping improve our patient and family experience. This year, you will have the opportunity to either serve with the Child Life Summer Volunteer Program or our traditional Summer Volunteer Program. The traditional Summer Volunteer Program will offer several volunteer opportunities throughout the hospital. Examples of shift experiences might include interacting with patients and families; participating in patient movie/craft/video-gaming events; cleaning toys; rounding up wagons and wheelchairs and escorting guests as needed; running an amenities cart to family rooms; or helping outside in the garden. ”
Pastoral Care/ Spiritual Support	Spiritual Care – “St. Jude has board certified chaplains ready help your family during all phases of your child’s treatment. They can provide spiritual and grief counseling, opportunities for worship, pastoral visits and sacraments. They are also available if you simply need someone to listen.”
Family-to-Family Mentorship Program	“The Parent Mentor Program matches parents of past patients with families who are walking through the doors of St. Jude for the first time. The program also matches newly bereaved parents with mentors who have also lost children. Mentors are St. Jude parents who provide support, encouragement and insight, helping families of newly diagnosed patients navigate their journeys through treatment. Mentors draw on their own experiences to provide a special connection for those trying to grow accustomed to a new way of life in the hospital or at home.”
Dedicated Activity Room(s) for Teens	Imagine Room – “The Imagine Room features a large interactive video screen that covers one wall and curves into the ceiling. In addition to playing games with the inpatients, a team of volunteers will lead arts and crafts, play movies, and assist patients in reaching friends and family through a webcam.”
Hospital School Program	School Program – “Licensed teaching staff are available to help your child maintain a familiar routine by providing academic instruction during treatment. They can also provide assistance and support to your child as they re-enter their school in your community. School liaisons are available to assist you in ensuring that your child receives any needed special services or accommodations to manage the long-term effects of their illness and treatment.”

Table 3.11 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Monroe Carell Jr. Children's Hospital at Vanderbilt, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(39)
Child Life Therapy	Child Life – "The Child Life Services department helps your child and family members cope with medical experiences. Our Certified Child Life Specialists are trained in child development and understand the unique needs of children, teens, and families in the hospital. Through play and education, Certified Child Life Specialists can partner with you to create a friendly and comfortable medical environment for your child."
Pet Therapy	Pet Therapy – "Pet team volunteers provide animal-assisted visitation in many areas of Children's Hospital. Our patients and their families love to interact with these gentle, highly-trained animals. Pet team volunteers visit patients and families in their rooms, greet them walking the halls, and provide comfort in our waiting rooms."
Art Therapy	Art Therapy – "Art therapists are mental health professionals trained in psychotherapy, art and the creative process. In a pediatric hospital setting, art therapy focuses on the whole family and strives to support the healing process by offering patients and their family members an opportunity for emotional expression, supportive processing and creative outlet. The process of making art is a natural form of self-expression. Art can be a way to communicate when it is difficult to find the words. During an art therapy session, patients are given the opportunity to make choices and gain control in an environment where they don't always have those options. Tapping into the creative process helps children, teens and their families work through the stresses of an illness and gives voice to unexpressed thoughts and emotions."
Music Therapy	Music Therapy – "Music therapists work with children of all ages and their families to create individualized interventions that may address chronic pain, physical rehabilitation, psychiatric symptoms, end of life, procedural support, and coping with hospitalization and disease. If your child has special medical, developmental or social needs, our board-certified music therapists can create a non-threatening, non-invasive program to help him or her better cope with being in the hospital."
Integrated Psychosocial Clinical Care Team (disease-specific)	Adolescent and Young Adult Cancer Program – "Adolescent and young adults with cancer have access to a comprehensive psychosocial support system, developed to assist all patients and their families during their cancer at Vanderbilt." This includes fertility preservation resources, financial counseling navigation, psychosocial resources, accessed to psychology resources, and the opportunity to connect with survivorship programs.
General Hospital Volunteer Program	College Volunteer Program – "All undergraduate college volunteer applicants must be available for two consecutive semesters (including Summer session) to begin volunteering. If you are unable to volunteer through Summer 2020, please wait to apply until Fall 2020."
General Hospital	High school STriVe program – "Strive offers a unique service learning opportunity for teens. The program fosters a commitment to volunteering, offers valuable insight into a variety of healthcare professions, and provides the opportunity to work in multiple areas of the hospital with patients, siblings, and family members. They work with mentors to plan, implement, and evaluate age-appropriate activities for patients and siblings in

Volunteer Program	pediatric playrooms and waiting rooms. They assist with cleaning toys, circulating the book and comfort carts, and conducting science experiments with patients.”
Pastoral Care/ Spiritual Support	Spiritual Care – “Children's Hospital understands the vital roles faith and spirit play in your family life. Our chaplains provide interfaith spiritual care while your child is here, ensuring you can connect with sources of hope and meaning. Chaplains are a helpful source of support at many moments: Needing prayer or spiritual guidance, Experiencing suffering or loss, Desiring a specific ritual, such as communion, baptism, or the sacrament of the sick or anointing, Wrestling with spiritual questions, unable to pray, a sense of being abandoned, a lack of hope or questioning the meaning of life, Needing information about community religious groups and resources.”
Media Studio/ Radio Station	Seacrest Studios – “Seacrest Studios is a partnership between Vanderbilt and Ryan Seacrest Foundation, which has been building broadcast media centers in pediatric hospitals across the country since 2010. Seacrest Studios at Children's Hospital gives children and teens the opportunity to express their creative side through radio, television and new media. Children can sing along with special musical guests, get behind the mic for radio interviews or try their hand at producing a television program. Every child in the hospital can laugh, learn and share in the fun through the hospital's broadcast network. The 723-square-foot multimedia studio has a full-time program manager who oversees activities including game shows, celebrity interviews, dance parties, lip-sync battles, bingo, educational series and live music performances.”
Dedicated Activity Room(s) for Teens	Teen Room – “Playrooms are just off the elevators behind the greeter's desk on each floor. If your child is restricted to his or her room, you may borrow toys and activities from the playroom. Volunteers may be available to play with your child in playrooms.”
Hospital School Program	Hospital School – “Our hospital school helps children keep up with schoolwork and maintain academic skills. We understand the importance of maintaining a routine and we want your child to return to school with as little stress as possible. Our Hospital School offers two ways to support patients – homebound support and K-12 tutoring.”

Table 3.12 Inpatient Programs Formally Offered to Chronically Ill Adolescents at Johns Hopkins Children's Center. Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	Program Name and Description(40,41)
Child Life Therapy	Child Life – "Our Child Life specialists work in the inpatient and outpatient settings to enhance the emotional and social well-being of your child and family throughout your health care experience. They use developmentally supportive play and other activities to help your child and you understand and prepare for treatments and procedures, before, during and after hospitalization. Child Life specialists also may assist you as your child transitions from inpatient to outpatient care, to home care and, eventually, to school."
Pet Therapy	Animal Assisted Therapy – "Animal Assisted Therapy offers our patients positive human-animal interactions in a clinical setting offering emotional support at a vulnerable time. Our teams visit both children and adults throughout Johns Hopkins Hospital on a regular basis. With more than 15 volunteers Therapy Dog teams in service, we believe that Animal Assisted Therapy improves the wellbeing of our patients, staff and family members. The human animal bond is a mutually beneficial relationship between people and animals that positively influences the health and well-being of both. Research combined with human intuition recognizes the impact the human-animal bond can have on health. Research has demonstrated where therapy dogs have positively affected patients' pain levels and satisfaction with their hospital stay; has significantly increased positive social behaviors among children with autism; has provided social support, lowered blood pressure, and made improvements in pain, mood and other measures of distress."
Art Therapy Music Therapy	Healing Arts Program – A music and art therapy initiative offered through Child Life, offering patients the opportunity to engage with local volunteer artists. Healthy Humor Red Nose Docs – "Johns Hopkins Children's Center partners with the Healthy Humor Red Nose Docs program to enhance the emotional and social well-being of your child and family by providing the comic relief so often needed during a hospital stay. Working in close association with Child Life Services, the clowns interact with clinical and hospital staff members to relieve each child's sadness, anxiety, isolation and even pain by diverting his or her attention during medical procedures. Part of a community outreach program of Healthy Humor Red Nose Docs, the clowns visit youngsters throughout the Children's Center, from the pediatric emergency room to pre- and post-op surgery suites and outpatient clinics, three days each week."
General Hospital Volunteer Program	Child Life Inpatient Volunteers – "Volunteers on the inpatient unit assist in the play area or at a child's bedside by encouraging activities between children and families with the use of play and recreational activities. These activities may include holding infants and toddlers; working on developmental milestones with infants and toddlers such as putting things in and dumping them out; learning to sit or stand; reading stories; playing board games; facilitating arts and crafts activities; or assisting with homework."
Pastoral Care/ Spiritual Support	Spiritual Care and Chaplaincy – "The Pastoral Care Department provides emotional and spiritual support to children and their families throughout their visit/stay in the hospital. Each Chaplain values and respects our families' beliefs. Chaplains offer a caring presence in a challenging time by: Providing encouragement and a calm presence around a time of concern or crisis, Praying with you and for you, Offering a listening ear and

	reflective conversation, Arranging for rites and rituals of your particular faith community, Offering bereavement support in or around the time of crisis or end of life, Discussing concerns during your hospital stay"
Media Studio/ Radio Station	CCTV Shows – "The Child Life TV program, staffed by a video producer and a special events/CCTV coordinator, provides weekly offerings such as Hospital BINGO, Clown Care News and The Cooking Show, as well as other seasonal programming. In each experience, the child has a role, whether it be looking for the medical items on their BINGO board, creating their own snack in the Cooking Show, helping the clowns perform magic or calling in to ask questions of special guests. Children also have the opportunity to appear on CCTV programs or help with their production. By participating, children interact and socialize with others, enhancing their self-esteem and creating positive memorable experiences during their hospitalization." There is a teen-specific show, "Teen Time" every Friday.
Dedicated Activity Room(s) for Teens	Teen Rooms – The Children's Center has two teen rooms. These spaces are considered "safe." No invasive procedures or confidential conversations should take place in these areas.

Table 3.13 Predictors of QoL or HRQoL among Chronically Ill Adolescents for Select Categories

	Categories of Predictors of QoL or HRQoL among Chronically Ill Adolescents (Counts of articles reviewed citing predictors in the category)		
	Use of Coping Strategies (40)	Psychosocial Factors (61)	Mental Health Status of Adolescent (76)
Predictors Cited	Active coping	Social and emotional support available to teen	Self-esteem
	Secondary control coping	Social and emotional support available to teen's family	Mental health status, psychological well-being
	Emotion-focused coping	Parental conflicts	Depression
	Spiritual coping	Public perception of the disease	Ability to concentrate
	Religious coping	Parental unemployment	Anxiety
	Wishful thinking	School participation	Psychological factors
	Distance	Number of school days missed	Distress from illness uncertainty and intrusiveness
	Praying	Achievement of educational and vocational milestones	Catastrophizing
	Acceptance	Dating anxiety	Psychological comorbidities
	Self-focus	Use of social networks	Use of psychological therapies for pain management
	Cognitive behavioral therapy	Psychosocial education	Stress
	Use of therapy for pain reduction	Number of missed work days	Perceived impact of disease
	External locus of control	Loneliness	Perceived impact of treatment regimen
		Social functioning; ability to socialize	Beliefs about illness
		Anxiety about telling peers about illness	Psychological flexibility
		School functioning	Cognitive and emotional issues

		Interpersonal relationships associated with pain coping	Presence of personality disorder
		Vulnerability	Life satisfaction (present and future)
		Family warmth and caring	Resilience
		Family support	Body Image
		Peer support/ rejection	
		Family psychosocial environment; family functioning	
		Ability to engage in day-to-day activities	
		Inclusion of friends in the treatment and disease management processes	
		Sexual adaptation	
		Development of romantic relationships	
		Social maturation	
		Identity formation	
		Development of autonomy/ independence	
		Psychosocial adjustment skills	
		Psychosocial distress	
		Having a personal confidant	
		Supportive services	
		Receipt of psychosocial guidance	
		Family adaptability	
		Counseling and education about disease	

Table 3.14 Characteristics of interviewed patients (n=9)

Patient Characteristic	Average (Range or Percent) n=9
Age When Interviewed	22.4 years (18-25 years)
Gender	Female: 4 (44.4%) Male: 5 (55.6%)
Hospital admissions since introduced to Streetlight	7 admissions (2-16 admissions)
Streetlight Encounters per Admission	5 visits (1-10 visits)
Total Streetlight Encounters during All Admissions Since Introduced to Streetlight	41.7 visits (5-162 visits)
Average Length of Stay in One Admission	9 days (2.4-21.8 days)
Max Length of Stay in One Admission	27.3 days (7-98 days)
Total Length of Stay since introduced to Streetlight (not consecutive)	73.2 days (12-228 days)

Table 3.15 Characteristics of Interview Patients with the Fewest and Most Streetlight (SL) Encounters

Patient ID	Age	Gender	Hospital Admissions Since Introduced to SL	Average SL Encounters per Admission	Total SL Encounters during all Admissions	Average Inpatient LOS (days)	Max Inpatient LOS (days)	Total Inpatient LOS (days)
A	22	Female	2	2.5	**5**	8	15	16
B	19	Male	16	10.13	**162**	14.25	64	228

Table 3.16 Themes and Subthemes Related to Coping Skills

Themes and Subthemes	Role of Streetlight (SL)
Hospitals are boring, isolating, hard	SL keeps me company
Hospitals are boring, uncomfortable, hard	SL provides distraction from medical setting
I feel stuck	SL is "fun"
I feel lonely/isolated	SL gives me something to look forward to
Watching TV all day is boring	
Adjusting to being away from home	SL helped ease the burden
I no longer live at home (i.e., college, etc.)	SL made treatment easier
The hospital is my second home	SL helps ease the anxiety
Adjusting to managing my own illness	SL creates a nice atmosphere
Learning to manage my illness	SL helps life be normal
Pain	SL helped with resilience
Symptoms are unpredictable	

Table 3.17 Themes and Subthemes Related to Psychosocial Factors

Themes and Subthemes	Role of Streetlight
Family involvement in care	SL is like a family
Family/parent involvement	SL provides community
Sibling involvement	SL goes out of their way
Family can't always be with me	SL tries hard to understand
Family assistance from SL	SL is intentional
Family positive feelings of SL	Connect with SL
Tired of my parents	Creating family
Friends	SL is relatable/on my level
Cannot be with my friends	SL is relatable
SL volunteers are my friends	SL volunteers are about my same age
My friends don't understand	SL got to know me as a person/identity outside of illness
Social media shows me I'm missing out	SL was persistent/creative with me
Hanging out in a group	SL is non-medical
I connect with SL	SL does not flinch
Appreciation for SL volunteers	SL helped with spiritual stuff
Patients getting to know each other	SL people are good/nice
SL volunteers bond with patients	SL is reliable
Talking/telling stories with SL volunteers	
Medical transitions are tough	Recalling specific, positive, SL memories/stories
Inpatient/outpatient	In-room activity
Pediatrics/adult care	Out of room activity
In/out of school	Off-campus activity with SL
Being a teen/being sick	Participate in charity walks with SL
	Seeing SL outside of the hospital
	SL engages me in my chronic illness community
	SL goes beyond the hospital
	Waiting for SL to arrive

Table 3.18 Themes and Subthemes Related to the Mental Health Status of the Adolescent

Themes and Subthemes	Role of Streetlight
Agency/Independence/Sense of Self	SL provides hope/joy/inspiration
I feel like a child/my identity has been stripped from me	SL helps with the mental space
Self-esteem/self-image/self-conscious	SL is "magic"
SL doesn't judge me/they accept me	SL inspires me
Feeling down/depressed	SL volunteers give me hope
Depression	SL cheers me up
Isolated	SL empowers me
Bummed with SL isn't around on weekends	SL advocates for me
I am a burden to others	SL is medicine/treatment for me
	SL helps change my perspective
	SL supports me

Table 3.19 Sampling of Quotes from Interviewees, by Category

Category	Theme	Quotation
Use of Coping Skills	Hospitals are boring, isolating, hard	"It feels so welcoming to have someone come in after sitting there for so long, feeling so bored."
	SL keeps me company	"I know they're always here…"
	SL keeps me company	"You know you have something to look forward to, like, "hey, I've had a really bad day and you know I don't feel good," but I know Streetlights gonna come, you know, at night…"
	Adjusting to being away from home	"I'm thinking about how just transitioning to college is already challenging itself, and then you add on, you know, getting this diagnosis."
	Adjusting to managing my own illness	"It was because, you know, it was in front of everyone. So everyone knew I had a feeding tube and everyone knew I had this problem, and everyone started looking at me differently."
	Adjusting to managing my own illness	"So she (SL) sat there while I was getting the other IV. They had a hard time putting it in…it was very painful. And she sat there and pulled up pictures of dogs on her phone. I love dogs and she tried to distract me, and you know, make sure I was comfortable as I could be. It was nice to have a distraction."
	Adjusting to managing my own illness	"And one of the Streetlight people found out about it and came by to just sit and watch music videos. And, you know, that really helped because it's really nice and it was uncomfortable…I got the abdominal port placed and it was extremely painful. So, you know, it helped."
	SL helped ease the burden	"…just hang out with that could share similar stories or tell me where they've been. And it wasn't all just focused on how I feel and doctors coming in and what was going on."
	SL helped ease the burden	"I don't think I would have been as positive or healthy getting through everything. I think I would have struggled more."
Psychosocial Factors	Family involvement in care	"We don't live in Gainesville, we live in [city], and sometimes we can't line up the sitter for my sister so she's had to come with us. And sometimes [Streetlight] will take her down to lounge and play video games with her and someone else will come in and sit with me so that also gives my mom a break too from everything."
	Family involvement in care	"…or I was tired of my parents, you know, or I just needed a break."

	SL is like a family	"because you don't have your mom…you always seem really nurtured and cared for by them."
	Friends	"It's really hard to function, you know…especially as a teenager. I'm in high school, you know, and my friends want to go out and eat burgers and fries – all greasy food, and I can't participate because it makes me sick…"
	Friends	"But I remember feeling a little more open with them than even some of my close friends."
	SL is relatable/on my level	"I know there's some people in Streetlight, like, you know, that are themselves, like, managing a chronic illness. And you can still go to college."
	SL is relatable/on my level	"…to get on the same level as the patient and really engage the patient, so they don't feel like they have to put on an act."
	Transitions are tough	"…for me, it was early high school. Everyone is just trying to see where they're fitting at that point in life, and when you're kind of stripped of that…"
	Recalling specific, positive SL memories/stories	"I was in the hospital for my birthday this year and last year and, you know, they make a banner and throw you a party."
	Recalling specific, positive SL memories/stories	"Again, I don't really remember much at all of that particular visit, other than the fact that this person, I never met before – came in to play the guitar. He played the guitar, and played it rather well. I asked him how long he had played for. And the response was that he never played before. This was his first time. I just remember laughing from that."
	Recalling specific, positive SL memories/stories	"And just anytime I was in the hospital after the buy in - I always asked for them, and if they were in, what time were they coming."
	Recalling specific, positive SL memories/stories	"They threw me like a Christmas, and that was really cool. They had like a little tree, and we got to decorate it and stuff like that."
Mental Health Status of Adolescent	Agency/independence/ sense of self	"I feel very much like a child."
	Agency/independence/ sense of self	"Yeah, I don't. I'm just super self-conscious about it now. Um, so I try to avoid sleepovers at all costs."
	Feeling down/depressed	"I know myself, I had a lot of anxiety, depression, a lot of things going on."
	SL provides hope/joy/inspiration	"And [Streetlight's] really just shown me that a really, really dark time – it can be really profound, with brightness and hope…"
	SL provides hope/joy/inspiration	"The point is…I just didn't see it coming [for him to have cancer too] when he walked in and he looked so good."

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CHAPTER 4. HOSPITAL PROVIDERS' AND ADMINISTRATORS' PERSPECTIVES OF STREETLIGHT'S ABILITY TO ENHANCE QUALITY OF LIFE AND HEALTH-RELATED QUALITY OF LIFE FOR CHRONICALLY ILL ADOLESCENTS

ABSTRACT

Background: This chapter summarizes findings from interviews with providers and hospital administrators at UF Health Shands Children's Hospital. The first half of the chapter examines their perspectives into the role of all inpatient program offerings that support patients, families, and providers at UF Health Shands. The second half of the chapter offers a case study specific to the 1:1 peer support volunteer program, Streetlight. This includes an analysis of providers' and administrators' perspectives on the impact of Streetlight on quality of life (QoL) for adolescents with chronic illnesses. The analysis focuses on predictors identified in the literature in Chapter 2 and focuses on three main factors: adolescents' use of coping skills, psychosocial factors, and their mental health status.

Methods: Interviews were conducted with clinical providers and hospital administrators at UF Health Shands Children's Hospital. The most senior individuals in each of eight roles: hospital executive, hospital administrator, social worker, nurse, physician, pastoral care staff, Child Life staff, and clinical technician were identified and interviews were scheduled. Individuals could select a designee if they were unwilling to participate or felt they could not meaningfully speak about program offerings. Interviews were recorded and transcribed. Interview data were analyzed according to thematic analysis in two domains: A) their perspectives into if/how a range of inpatient programs at UF Health Shands support chronically ill adolescents, their families, and the providers who collaborate with programs, specifically focused on QoL; and B) their perspectives about Streetlight, a 1:1 peer support volunteer program, specifically examining

how the program impacts predictors of QoL and health related quality of life (HRQoL) for adolescents with chronic illnesses, including the use of coping skills, psychosocial factors, and the mental health of the adolescent.

Results: Among the eight individuals invited to participate, three offered a designee in the same or similar role to participate in their place. The findings from analysis A suggest the inpatient support programs offered to chronically ill adolescents at UF Health Shands Children's Hospital provide support for the adolescent patients, and for their families and the hospital providers who care for them. In addition, the programs described by providers were found to enhance QoL for patients, family members, and providers. Analysis B examined providers' perspectives of the Streetlight program specifically, and found that Streetlight: 1) helps adolescents cope, 2) helps to meet the psychosocial needs of adolescents, and 3) positively impacts adolescents' mental health.

Conclusions: Provider and staff at UF Health Shands Children's Hospital believe that the inpatient support programs offered to chronically ill adolescents that seek to enhance QoL and/or HRQoL are important and effective complements to the resources provided by clinical care teams in the inpatient setting. As hospitals increasingly aim to provide high-quality patient- and family-centered care, they may also consider whether similar programs should be incorporated into the treatment protocols.

Keywords: adolescent, teenager, psychosocial, well-being, chronic illness, chronically ill, palliative care, quality of life

Running Title: Hospital Providers' and Administrators' Perspectives of Inpatient Programs, including Streetlight, at UF Health Shands

4.1 Background

As detailed in Chapter 2, children's hospitals are increasingly offering programs in the inpatient setting to enhance adolescent patients' quality of life (QoL) and to similarly support their family members.(1-4) In some cases, these programs also collaborate with and support clinical providers, including doctors, nurses, social workers, and others who are part of the patients' care team. Given multiple competing priorities and mounting demands on providers' time, these programs can complement the care the clinicians provide.(5,6) Inpatient programs may need to offer additional resources to patients, beyond those provided by the medical providers.

Similar to Chapter 3 in which UF Health Shands patient perspectives were examined, this chapter assesses the perspectives of the hospital's providers and administrators in the same hospital. Together with the feedback from patients, the insights of providers and administrators will be useful in assessing whether they believe these programs benefit adolescents with chronic illnesses, and the extent to which the programs offered enhance QoL. When examining QoL as it relates to individuals with chronic conditions, their health-related quality of life (HRQoL) should also be considered. HRQoL was established to describe health status measures from a patient's perspective.(7) This includes, for example, the extent to which one values their health and how well someone feels they function in terms of their perceived wellbeing.(7) The concept and use of the term "QoL", beginning in the 1960's, preceded the use of HRQoL.(7) The terms are often used interchangeably in the literature today, creating some confusion.(7) In this thesis, both terms were included in Chapter 2's review of literature to identify adolescents' predictors of QoL. In addition, the inclusion of both terms in the review, and in the qualitative analyses in Chapters 3 and 4 is meant to ensure that all aspects of chronically ill adolescent's quality of life

are considered – whether focused specifically on their health condition or otherwise. Given the focus on adolescents with chronic illnesses, it might be difficult to separate out an analysis of QoL and HRQoL, which likely overlap and which are likely to be co-mingled in adolescents' comments and insights.

A review of existing literature in Chapter 2 found that chronically ill adolescents' predictors of QoL can be grouped into seven categories. These include demographics,(8-13) use of coping strategies,(14,15) psychosocial factors,(16-18) disease control and management,(19-22) the mental health status of the adolescent,(11,18,23-27) the mental health status of the caregiver,(12,28) and the physical environment.(29) Among these, this study focuses on the patient's use of coping strategies, psychosocial factors, and the adolescent's mental health status.

As described in Chapter 2, these three categories would be most actionable for hospitals. The predictors related to demographic characteristics (i.e., age, birth weight), the mental health status of the caregiver (i.e., better parental adjustment, parental distress), and the physical environment (i.e., seasons) are all categories that cannot be easily addressed by the hospital or the programs. To retroactively address these factors would not impact the present circumstances of the adolescent. Factors such as parental adjustment, however, could be addressed moving forward, as a factor for which the adolescent's QoL may be impacted. Disease control and management was also excluded, as it does not represent a social need. It was assumed that all children's hospitals strive to provide high-quality, comprehensive, medical care.

Three hospitals included in the review offer a 1:1 peer support program to adolescents in the inpatient setting (refer to Table 2.0). These include Wolfson Children's (Emerging Pediatric Professionals – EPP), UF Health Shands Children's Hospital (Streetlight), and University of North Carolina Children's Hospital (Carolina Pediatric Attention Love and Support – CPALS).

These programs share several commonalities. First, all three programs leverage student volunteers from nearby undergraduate universities. Emerging Pediatric Professionals is solely open to students at the University of North Florida School of Nursing.(30) Streetlight and CPALS are both available to students of all majors at University of Florida and University of North Carolina, respectively, though many volunteers tend to express interest in exploring a health profession.(31,32) In addition to being a source for 1:1 companionship, they also offer adolescents the opportunity to participate in social activities such as game nights, trivia, video game competitions, and other similar activities.

Though they all seek to provide support to patients, all three programs have marked differences. While all are offered to adolescent-aged patients, Streetlight is the only program that targets adolescents and young adults specifically. Patients are eligible to participate in Streetlight only if they are between the ages of 13-29.(31) CPALS and EPP are open to pediatric patients of all ages. Streetlight and EPP serve patients of all chronic illness diagnoses, while CPALs partners with patient who have a diagnosis in hematology/oncology only.(32)

The programs have also been in existence for different amounts of time. CPALs has been operating for 25 years, though the program as it operates today was largely formed in the last decade.(32) Streetlight has been operational for 14 years.(31) EPP has been operational for approximately a year and a half.(30)

Given Streetlight's specific focus on adolescents and young adults, broader engagement with patients regardless of chronic illness diagnosis, and 14-year operations as a 1:1 peer support program, providers and staff at UF Health Shands may be able to offer a more comprehensive insight on adolescents and young adults than their counterparts at the other hospitals. Streetlight has had a well-formed presence in the hospital and has received an increasing number of

referrals in the last 10 years.(31) Further, given that the eligibility criteria includes all chronic conditions, providers of varying backgrounds may offer insight across a broader population of adolescents and young adults than the other programs. The perspectives of hospital administrators, healthcare providers, and other licensed healthcare professionals about the role of Streetlight at UF Health will help to illuminate the ways in which they believe the program impacts the QoL and HRQoL of the patients they serve, and may uncover new ideas and/or themes that might be important for healthcare institutions to consider when making decisions about the programs they offer patients. These individuals are likely to understand the impact that managing a chronic condition has on an adolescent, and may be able to offer empathetic perspectives that are informed by their knowledge of the diseases.

4.2 Study Design and Population

Interviews were sought with the most senior individuals in each of the following roles at UF Health Shands: hospital executive, hospital administrator, social worker, nurse, physician, pastoral care staff, Child Life staff, and clinical technician. Interviewees were required to have had interaction with the Streetlight program in some capacity for at least 4 months, either administratively, or having referred patients in their care to Streetlight. The most senior person at UF Health Shands in each of these roles was contacted by a team of researchers at UF Health, and asked to participate or to offer a designee familiar with the program. At the conclusion of interviews, individuals were asked to provide the name of anyone else who might be able to offer insight about the Streetlight program specifically. Among the eight interviewees, two provided names. The named individuals happened to already be in the sample of interviewees. Most interviewees, when asked, explained that given the circumstances surrounding COVID-19, providers might not be able to find the time to participate. This may have contributed to the lack

of referrals they offered. Interview transcripts were de-identified to anonymize any comments which might reveal interviewees' identity. Among the initial recruits identified, those in the roles of hospital administrator, pastoral care staff, and Child Life staff offered the name of a designee in the same or similar role for outreach. All other initial recruits agreed to participate themselves.

4.3 Methods

Interviews were conducted via Zoom, an online teleconferencing tool. Participants were consented into the study prior to the interview, and again at the start of the interview. Open-ended questions guided the discussion (refer to the interview guide in Appendix A), and interviews were between 45-60 minutes in length. Interview questions sought to understand the interviewee's role at UF Health, and the interaction they had on a daily basis with adolescent patients and/or the programs offered to them. Next, interviewees described their knowledge of all of the programs available to adolescents with chronic illnesses at UF Health Shands. They were asked to share whether they felt UF Health had particular strengths as well as gaps in any of their program offerings.

The next section of the interview was specific to the Streetlight program. Interviewees were asked to describe their understanding of the program, including what they felt the program offered patients and how the program compares with other offerings at UF Health. In some cases, they were able to offer comparisons to program offerings at other children's hospitals, if they had experience working at another hospital. In addition, they provided examples of how Streetlight volunteers and staff address psychosocial issues in comparison to how licensed providers address these issues. The final domain of interview questions centered on the program's sustainability and overall sense of support (financially or otherwise) from UF Health as an institution.

Analysis of the data was separated into two parts. In the first analysis (analysis A), data were analyzed to understand the impact of the UF Health Shands program offerings on providing support to 1) patients, 2) families, and 3) hospital providers and staff. The second analysis (analysis B) is specific to the Streetlight program. Specifically, this analysis sought to determine the extent to which providers and hospital administrators perceived Streetlight to impact chronically ill adolescents' QoL, specifically focused on use of coping skills, psychosocial factors, and mental health status.

Both analyses follow a general thematic analysis approach, as outlined by Braun and Clarke.(33) Braun and Clarke outline a series of phases to guide researchers through thematic analysis, helping to make the process replicable and transparent. This process includes familiarizing oneself with the data, generating a series of initial codes, analyzing the initial codes for natural groupings or themes, conducting an in-depth review of the themes, combining and assigning names to themes, and finally analyzing whether there is a series or hierarchy to the themes.(33) They describe themes as capturing important aspects of the data in relation to the research question, and representing some level of patterned response or meaning within the data set.(33)

Following this detailed approach, the transcripts were coded and analyzed using MAXQDA Analytics Pro 2020 (Release 20.1.0). First, transcripts were read several times in order to obtain an overall sense of the content. Next, the transcripts were examined slowly, coding sections of text that revealed important patterns in respondents insights (subthemes) as they related to the three categories of interest – use of coping skills, psychosocial factors, and mental health status of the adolescent. The focus on these three categories, as opposed to all

seven identified in Chapter 2, was deliberate, specifically seeking to understand how the information gleaned might suggest actionable results for hospitals.

Once all interviews were coded, subthemes were compared and combined if they represented similar ideas or thoughts. For example, one subtheme identified was "providers referring patients to programs" and another was "providers meeting with program leaders to review patients." These were combined to form the subtheme "programs collaborate and communicate with providers." Next, subthemes were formed into groups. For example, "programs collaborate and communicate with providers" and providers' noticing "I don't have time" both describe how programs support providers. These groupings of subthemes were then renamed, and were identified as the themes. In this example, the theme is "inpatient programs support providers."

All eight transcripts were included in analysis A and analysis B. All eight interviewees represented the roles of staff and providers for which interviews were sought. These included hospital executive, hospital administrator, social worker, nurse, physician, pastoral care staff, Child Life staff, and clinical technician. A faculty members at the Johns Hopkins School of Public Health who is well experienced in qualitative research and MAXQDA reviewed the codes. IRB approval for this study was obtained from both University of Florida and Johns Hopkins Bloomberg School of Public Health.

4.4 Results

A thorough review of the interview data revealed a variety of themes related to the positive impact of the inpatient program offerings to adolescents, their families, and the providers and staff who care for them. In the first analysis (analysis A), which broadly focused on all program offerings and their role in enhancing QoL, all eight interviewees spoke

specifically about how the programs impact patients, families, and providers. Themes by category and related subthemes are summarized in Table 3.0.

In the second analysis (analysis B), hospital providers and administrators focused specifically on Streetlight, and its role in enhancing QoL for adolescents. Similar to Chapter 3, the analysis specifically examined the extent to which they felt the program was able to address the adolescents' use of coping skills, psychosocial factors, and mental health status. Themes by category and related subthemes are summarized in Table 4.0.

Analysis A: Impact of UF Health Inpatient Program Offerings of QoL for Patients, Families, and Hospital Providers

1. Theme: Providers feel supported by inpatient programs

All eight interviewees described how inpatient programs for adolescents support hospital providers and clinicians in their roles. Subthemes from the transcripts include how programs collaborate with providers and references they made regarding how the clinicians and administrators don't have time to provide the added support to patients, given multiple competing priorities. One provider said, "Sometimes I just don't have the time to actually sit with a patient regularly to be able to process stuff." Clinicians described the ease of making referrals to Child Life, Streetlight, and Arts in Medicine, and the prompt and warm reception the staff offer patients once referred. They mentioned that Child Life and Streetlight staff often follow up with them to let them know whether a patient is engaged with the team. "…you know, [they both] have an office on the same unit that I do. So it's really easy to access them and for us to work together on patients." Providers were clear that they tend to refer most adolescents to Streetlight rather than Child Life, but care for patients engaged with one or both programs.

Some providers described how Streetlight staff attends weekly "rounds" meetings with disease-specific care teams, in which the team carefully reviews plans of care patient-by-patient. They suggested it was helpful to have Streetlight staff there, with notes about adolescent patients, in order to help comment on any underlying social issues the patient or family may be experiencing. "They tell them [Streetlight] different and more useful information sometimes…" They felt this additional information, which high-level, often helped in understanding patients' behavioral, mental health, or other aspects that contributed to their plan of care.

One provider explained that while "big picture" comments were helpful to the care team in a meeting setting, it was still important to them that the patient and volunteer be able to speak confidentially with each other at the bedside. "Well, I think that…the specifics…what they're talking about is really none of my business. And I tell them, 'you don't have to talk, I'm just going to be here for a second and then you guys can carry on' because it's important for [the adolescent and Streetlight volunteer] to preserve that relationship." Providers described, in different ways, working around program volunteers, trying to not "get in the way." They all felt the inpatient programs they described supported them in their role by offering additional resources to patients. All providers conveyed a sense of comfort and ease, knowing these supports were available to patients.

2. Theme: Inpatient programs support families

All eight interviewees offered comments about the programs' support of family members. Parents and siblings can often be overwhelmed, not only with their loved ones' diagnosis, but also with the multiple responsibilities they have in caring for them. Providers identified families' needs for various forms of support, including assistance navigating clinical decision-making, financial complexities related to insurance and long inpatient stays, caregivers' ability to take a

leave of absence from work, if necessary, financial assistance available to them from state- and local agencies, among others.

Given the myriad responsibilities families and caregivers face in navigating these issues, providers and administrators described how difficult it can be for them to also spend time at the hospital. One of the most frequently mentioned needs was the family's need to feel that their loved one would be okay if they weren't able to always be at the bedside. Providers offered high praises for Child Life, Arts in Medicine, Streetlight, and the general hospital volunteers, saying that often they focused more intently on adolescents who didn't have family or friends at the bedside. Providers felt that family members felt a greater sense of "peace and ease" know that there would be others at their loved ones' bedside, and that they would provide distraction, comfort, and companionship (even if in brief sessions). They noted that it seemed to lift weight off of parents and family members who were "especially ridden with guilt."

In other cases, family members receive direct assistance from Child Life and Streetlight. For example, providers explained how Child Life offers siblings counseling and education as they process their sibling's illness. About Streetlight, one provider told a story about how one mom was reluctant to ever leave her daughter's bedside. As she grew to know the Streetlight team, and saw how comfortable her daughter was, she began to see Streetlight's visits as an opportunity to take a break from the bedside and go for a walk outside or enjoy a cup of coffee in the cafeteria. In this way, the program was helping to address her needs as a caregiver.

3. Theme: Inpatient programs support adolescent patients

All interviewees described the various program offerings, although, in sum they did not mention all of the programs available. Most frequently referenced were Streetlight, Child Life, and Arts in Medicine. Other programs such as pet therapy and Hospital Homebound (hospital

school) were not mentioned by the majority of interviewees. This may be because the providers are less familiar with them, have a less established relationship with them, do not often make referrals to the other programs, or perhaps because they are less utilized by adolescents generally. It could also be that providers do not as readily associate those programs with predictors of adolescents' QoL, though this was not probed in the interviews. Except for Streetlight, all of the other inpatient program offerings are available to pediatric patients of all ages. None of these programs, however, are tailored specifically to meet the needs of adolescents and young adults.

One subtheme included that providers and administrators felt the programs provide support beyond what the clinicians can offer. They described the differences in working through a difficult time with a peer versus a clinician. One interviewee explained they were "old and gray, and certainly they don't…they can't relate to me." Other comments described the non-medical nature of hospital volunteers, who typically wear plain clothes are "less intimidating…since they aren't wearing white coats and stethoscopes and things."

Providers noted that "[these programs] continue through the transition process…the transition to adult care. So they're still present there – and play a role." The continuity of program offerings, and the ability for an adolescent to become familiar with something, and have it follow them through their care journey, perhaps suggests the stability is an important aspect of their care, from the providers' perspective.

4. Theme: Inpatient programs enhance QoL for providers, families, and patients

In addition to describing the role of these programs in supporting various stakeholders, all interviewees also commented about how these programs enhance QoL for patients, families, and even themselves specifically. Interviewees described how the ability to refer patients to these

additional resources helped them to feel more at ease, given they did not always feel they had the time to stay at the bedside for very long, getting to know the patient and their hopes and fears in depth. “I think that by helping our teenage patients it ultimately helps the team care for them better…If you think about the care of the child as being more a holistic approach then we all benefit from their involvement in their care.”

They also felt that these programs provided a sense of normalcy in the hospital setting, which they felt was important for the adolescents. Some offered stories about adolescent patients getting to know other adolescents in the inpatient setting, because a program hosted an event on a unit, creating an opportunity for them to meet.

Finally, providers were very aware of family members’ stressors related to not being able to be present, at the bedside, at all times. In many cases, they sensed a feeling of guilt from parents having to work or take care of other children. Providers felt families were grateful for the support of these programs, which were able to provide company and support to adolescents in their absence. This lead to an “eased burden” for family and caretakers.

Analysis B: Impact of UF Health’s 1:1 Peer Support Program, Streetlight, on QoL for Chronically Ill Adolescents in the Inpatient Setting

1. Theme: Streetlight helps adolescents cope

All eight interviewees remarked that the Streetlight program specifically helped adolescent patients cope with their illness or various aspects of their life that had been impacted by their illness. “One could argue that, especially for those with a chronic illness, spending much of your teenage years in the hospital is not ideal for so many reasons. To have this program that focuses on them – and that they know, and every time they come into the hospital…it’s a joy.” Providers said that Streetlight helped patients identify and describe their pain and other

discomforts. One provider also described how a patient continually told Streetlight about their frustration with the food options available to them, and ultimately helped the patient raise this with the care team. “These things are important for us to know… you know, they are already miserable sometimes. We want to make it as easy as possible to cope with the hospital setting.”

Participants reported that Streetlight offered patients opportunities to develop healthy coping skills such as listening to music, creating décor for their room, reading, learning to meditate, and laughing with other adolescents. Providers remarked that it can be easy for adolescents to slip into unhealthy coping patterns, especially when isolated, and that Streetlight offers a natural opportunity for healthy coping activities. They also commented about the example the Streetlight volunteers provide, particularly those who have chronic illnesses themselves. “They can see, you know, college students not much older than them, managing their disease and their lives just fine. They can cope a little easier with the reality that they’re sick, you know, but they can also have a normal life…when they can see other kids who have been successful.”

2. Theme: Streetlight provides friendship and companionship

All of the interviewees offered insights that related to Streetlight meeting the psychosocial needs of the adolescents. In particular, providers mentioned that Streetlight staff and volunteers are “non-medical,” making them more approachable in some cases, and certainly distinguishable from clinicians who often interact with them regarding clinical information, decisions, and test results. Providers also offered stories about patients being comforted by the friendship of Streetlight volunteers when their family members were not able to be at the bedside. This was perhaps the most prominent theme throughout the interviews. Providers felt patients greatly benefited from companionship, often noting they saw behavioral changes with

the patients who had established relationships with Streetlight. Patients referred to volunteers as their "friends," and providers told stories about Streetlight volunteers attending patients' birthday celebrations, end-of-treatment celebrations, and unfortunately, funerals in some cases.

> "He lived in a town near Gainesville, kind of out in the country. I went to visit him out there and there were several Streetlight volunteers out there interacting with him… it was a very light-hearted scene at his house because all of his friends were there and he was carrying on telling jokes. And two days later he died. But the whole time it was like that and he wanted it to be like that. He didn't want it to be a sad scene. And I think it wouldn't have been like that without those [Streetlight] volunteers."

Providers also recalled instances of Streetlight creating opportunities for patients to meet each other in group settings. Streetlight offers weekly "lounge nights," for example, at which adolescents can play games and get to know each other. In some instances, this has led to patients of similar ages and sometimes similar diagnoses becoming good friends. One provider offered a story about two boys who became "best friends" after meeting at a Streetlight event. They felt it made their inpatient stays less isolating, and were glad the boys had the opportunity to meet.

3. Theme: Streetlight positively impacts adolescents' mental health

All interviewees also offered insights into the ways Streetlight impacts adolescents' mental health status. Providers mentioned that adolescents with chronic illnesses often exhibit signs of depression and anxiety. "They are already feeling not in control, and then it's so lonely to be here too – sometimes they just don't have anyone to talk things through." They described Streetlight volunteers as being particularly skilled in listening and being a "sounding board." "I think sometimes [they] are just good at following the patient's lead, like listening to whatever

they have to say that day. They, you know…they just let them process stuff in the open without judging. I think they must have extensive training to be good like that. I'm [40+] years old. There's a lot of stuff they're not going to tell me. I'm old with grey hair. They need a friend." Another provider noticed:

> "They are not medical, so they really serve as a support for the patients. The things they talk about are not documented in the medical record, and in fact, are not shared with the medical team. This is a relationship that develops between the student volunteer and the patient that is protected…it's a relationship they develop that allows for the kid to have some trust in this person who is coming to see them all the time."

Additional comments focused on how Streetlight offered adolescents help "getting out of a funk" or a "dark place." Most notably, providers explained that the distraction activities with volunteers were always incredibly helpful. "You can almost notice right away, like after 20 minutes of the [Streetlight] volunteer showing up. [They] stop their spiral, and…become like a happy teenager again." Some of these activities include playing video games together, listening to music, making posters, and talking about sports or other shared interests. Providers stressed the importance of a positive mindset, especially among chronically ill teens. Some mentioned that Streetlight helped patients "have a will to, or want to, live…like really live. And that is so important here because these are tough diseases, and some days it's okay and other days it's just crummy and really tough. And so their mindset is so important, you know, to get them through."

4.5 Discussion

These findings are an important contribution to the literature in that they go beyond the focus on patients, seeking to understand whether there are similar benefits to patients' caretakers. The inclusion of hospital providers' insights about the roles of various inpatient support

programs builds on the input patients provided in Chapter 3 about the ways in which their care is enhanced by these offerings.

The findings in analysis A detail how providers and administrators feel inpatient support programs benefit patients and those caring for them. They described the ease with which they refer patients to programs and the prompt outreach process. For many providers, this is done by placing a phone call, generating a referral in the electronic health record, or even walking down the hall when program staff share office space on the unit. “I like to check back in, after they see them, to see if they think [the program] might be a good fit.”

In addition, the analyses described the providers’ perspectives of the ways these program assist families. They mentioned the familiarity program staff often have with the complex issues, such as finances, employment, and assistance with care for siblings, for example. While social workers and other hospital staff typically engage in these discussions with families, program staff have also helped to navigate and connect families to appropriate resources.

This analysis also captured providers’ perspectives of the programs’ abilities to support the adolescents directly. Notably, providers only referred to a small handful of the programs available to adolescents at UF Health Shands. These included Child Life, Streetlight, and Arts in Medicine. It is possible that they are most familiar with these programs, or perhaps these programs have more resources than others, and therefore are more prominent to providers and staff. It also may be that these are the main programs providers think about when discussing QoL topics, and that perhaps other resources such as the hospital school program did not come to mind. UF Health Shands may seek to better understand providers’ interactions with the programs that were not mentioned, in order to maximize their utility for adolescents in the inpatient setting. These analyses do not suggest there are unmet needs for adolescents based on the identified

predictors of QoL. From a strategic business perspective, however, it would be beneficial for UF Health Shands to compare the needs the other programs are addressing with providers' and patients' perspectives of the programs.

Overall, providers described these programs as offering staff and volunteers who were "relatable" and who were closer in age to adolescents than most members of the clinical care team. They saw this as being a benefit to establishing friendships and connections. They also described the sense of normalcy they felt these programs provided patients, offering glimpses of adolescence that are often missing from the somewhat isolating and steril medical setting. A few of the providers discussed adolescents' transitions to adult care, commenting on the benefit of these programs being a steady source of support for patients as they transition to new care teams.

Finally, analysis A described the role of inpatient support programs in enhancing QoL for providers, family members, and patients alike. While all three groups have different perspectives and needs, it is particularly noteworthy that they all felt the presence of these inpatient programs provided them a direct benefit. Providers reported being glad their patients' psychosocial needs could be addressed, even if they did not feel they personally had enough time to spend at the bedside. Providers felt family members were especially relieved to know that their adolescent would be well-supported even if they could not be at the bedside. Lastly, providers expressed the positive impact of the programs on enhancing the QoL of patients themselves, providing a sense of normalcy and some of the same types of activities adolescents would experience in social settings with friends. They commonly described benefits as "easing stress," "creating a supportive environment," and "providing undivided attention" regardless of who they were referring to. "We all benefit from [these programs] being here."

Analysis B focuses more specifically on the Streetlight program, evaluating the ways in which a 1:1 peer support program specifically addresses adolescents' QoL in three domains. Similar to the findings in Chapter 3, the interviewees in this study offered the most feedback and commentary regarding Streetlight's role in addressing patients' psychosocial factors. In this analysis, the specific theme was centered on dimensions of friendship and companionship, and social interaction with other people of similar ages.

Another theme identified focused on Streetlight helping adolescents cope and, by nature of the program, offering healthy coping strategies. Providers interviewed felt the adolescents benefited particularly from interacting with peers of similar ages who, themselves, were living with chronic conditions and were now undergraduate students.

They spoke about how their examples helped the patients cope with their circumstances, and the realization that they may also be able to attend college despite the limitations of their illness. Provides described how difficult it can be to see patients process the physical and emotional effects of living with a chronic illness, and often, spending extended periods of time in the inpatients setting. "[These] kids are in pain, and then having Streetlight volunteer come in, you know, to help at least distract them, you know, in that moment."

Finally, analysis of the interview data identified a consistent them around Streetlight helping to positively impact adolescents' mental health. While providers interviewed generally felt the hospital's psychologists, psychiatrists, and other licensed clinicians were able to address adolescents' mental health issues, most commented that the value of Streetlight is the non-medical presence the volunteers bring to the bedside. They felt their support enabled patients to be vulnerable in ways not often seen by clinical care teams. Across all 3 themes, interviewees

saw Streetlight as complementing the services provided by licensed clinicians, providing enhanced QoL for adolescents engaged with Streetlight volunteers.

When asked to describe any negative aspects of the program, some interviewees said they felt it would be helpful to have access to the Streetlight volunteers for more than simply the evening shift (typically 5pm-8pm). This was described as being for two main reasons. First, providers suggested patients would benefit from having more access to and interaction with Streetlight beyond the evening shift. Second, providers wished they could have more "face time" with Streetlight volunteers, and perhaps indirectly observe and interact with volunteers in the hallways, for example. Along these same lines, another stated opportunity for Streetlight was to perhaps involve them in a more formal way in team rounds. Certain disease-specific teams have incorporated Streetlight staff into their weekly meetings, while others have not. Providers felt increased communication and collaboration regarding patients, especially any insight they might be able to offer about patients' view, might help the clinical teams to tailor their care to their needs even more than they already do.

4.6 Limitations

There are limitations to this study. First, it is important to note that this study is restricted to data from interviews with eight hospital providers and administrators. A small sample size increases the likelihood of identifying themes in the literature that may not represent the viewpoints of hospital staff broadly. To minimize this, interviews were sought with individuals in varying roles so as to draw on perspectives across the hospital staff. Further, the sample of interviewees are all from the same institution, thus providing a small snapshot of the greater realm into a single children's hospitals in the southeast U.S. While participants were asked to participate based solely on their role at the hospital and their familiarity with inpatient programs,

there remains a chance for selection bias among those who agreed to participate. To minimize the potential for this, the interview guide posed open-ended questions, asking specifically for positive and negative viewpoints and stories or examples that supported their insight (i.e., "Can you please tell me about a time when…."). Refer to the Interview Guide in Appendix A. The majority of comments provided about the programs were overwhelmingly supportive and positive. It is possible those who may have had different impressions were not included in the sample. Additionally, some of the interviewees refer patients and interact with these programs multiple times per day, and others barely interact with them. Given this, their impressions could have varied based on their exposure alone. Although interviewees were given assurance that their responses would be anonymous and no statements would be attributed to them specifically, they could have felt pressure to provide socially desirable responses to interview questions, and potentially not share more honest critiques. This leads to possible response bias.

Finally, given the small sample of interviewees and time constraints, analyses and coding were conducted by one person. While codes were checked by a faculty member at the Johns Hopkins School of Public Health, there is difficulty in establishing inter-rater reliability, or the agreeance of more than one analyst in applying the same set of codes. In coding data, it is ideal to have more than one coder "agree" by applying the same codes to the data, thus drawing the same conclusions. A strong degree of inter-rater reliability suggests there is consensus, while the application of dissimilar codes, leading to differing themes, would lead researchers to question the validity of the analysis.

4.7 Conclusions

This analysis provides insight into the ways in which hospitals seek to enhance QoL for patients and their caretakers. Not only are children's hospitals increasingly offering patient- and

family-centered care,(34,35) but they are also perhaps offering provider-centered care, directly and indirectly, by offering these programs. In addition, many hospitals have prioritized specific initiatives for providers and hospital staff, such as the Joy of Medicine.(36) This, and other similar workplace well-being initiatives seek to mitigate burnout among providers and focus on strategies to cultivate resilience.(36) As pressures mount to address the myriad psychosocial factors that patients and their families face, hospitals are seeking opportunities to acknowledge the emotional impact of providers' care for their patients and offer channels of support to enhance their QoL.(36) Inpatient program offerings that seek to enhance QoL for patients may also serve the needs of family members and members of the patients' care team. The impact of such programs should be considered across all three populations, especially in seeking to evaluate a program's effectiveness for all involved in the patient's care journey.

In the same patient- and family-centered care arena, in the last two decades, hospitals have begun to pay more attention to quality improvement activities, of which patient satisfaction plays a key role.(37) Patients and their family members are asked to complete satisfaction surveys to offer feedback about their experience, in efforts to provide the hospital with critical information regarding the quality of their experience. Patient satisfaction scores have been found to affect clinical outcomes, patient retention, and even malpractice claims.(38) Hospitals may consider whether offering resources such as those described in this chapter may help to improve patient satisfaction and the overall quality of care patients receive.

Programs offered to chronically ill adolescents at UF Health Shands Children's Hospitals help to enhance QoL for patients, families, and providers. As hospital leaders and decision-makers evaluate opportunities to offer programs to enhance QoL for patients, they should consider whether there are certain programs that could similarly enhance the lives of family

members and hospital providers. From a decision-making standpoint, understanding that hospital resources are not infinite, an analysis to determine a programs' return on investment might be of value to leaders.

4.8 Tables

Table 4.1 Inpatient Programs Formally Offered to Chronically Ill Adolescents at UF Health Shands Hospital, Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

Assigned Group	**Program Name and Description**(31,39)
Child Life Therapy	Child Life – "Child Life Specialists at UF Health Shands Children's Hospital are certified professionals who work in partnership with families, doctors, nurses, and other caregivers to meet the unique emotional and developmental needs of children and families. Child Life Specialists at UF Health Shands Children's Hospital: Provide age-appropriate play and activities to promote coping, expression of feelings, and adjustment to the healthcare setting; Prepare, educate, and support children undergoing medical procedures and treatments to help them understand what to expect, clear up any misconceptions, and build healthy coping skills; Provide support and distraction for patients during medical procedures; Provide non-threatening, age-appropriate explanations and preparations; Help children understand diagnosis or illness; Promote normal growth and development; Offer legacy building and memory making to help children cope with grief; Develop supportive relationships with patients and families and promote family centered care"
Pet Therapy	Pet Therapy – "Behind each volunteer (human and canine) and every single volunteer hour, there is a story. All of our pet therapy volunteers have great love for animals and a great desire to help our patients."
Pet Therapy	Personal Pet Visitation – "At UF Health we understand that pets are an important part of our lives and our healing. For our long-term patients we provide an opportunity to include personal pet visitations with dogs as part of the hospital stay because we know that sometimes a visit from our favorite dog is just what the doctor ordered. Personal pet visitation allows for the patient's own dog to visit him/her in the hospital, while making sure we maintain the health of our pet therapy volunteers and our patients."
Art Therapy Music Therapy	Arts in Medicine – "From humble beginnings, UF Health Shands Arts in Medicine has grown into one of the largest comprehensive arts in healthcare programs in existence. Starting with two volunteer visual artists working on the Bone Marrow Transplant Unit, Arts in Medicine now has 16 paid artists in all art disciplines working in six separate buildings throughout the UF Health system, covering the Gainesville and Jacksonville communities. Our programs are designed to transform the hospital experience for patients, visitors, caregivers and staff. We focus on the following areas: the visual arts, the literary arts, the performing arts, and design and aesthetics."
Integrated Psychosocial Clinical Care Team (disease-specific)	Adolescent and Young Adult (AYA) Cancer Program – "The UF Health AYA Cancer Program addresses the compelling and unique medical and psychosocial needs of our adolescent and young adult patients — from diagnosis to survivorship. This includes needs such as fertility preservation counseling, age-appropriate distress screening, psychosocial support, career/vocational resources, family-building options in survivorship, increasing access to clinical trial participation and multidisciplinary care. With this support, the UF Health AYA Cancer Program hopes to help break down the barriers to effective treatment commonly experienced by this distinct population, giving each person the best chance at beating his or her disease."

General Hospital Volunteer Program	Degree-Seeking and Non-Degree Seeking Hospital Volunteer Program – "Degree-Seeking volunteers are asked to commit to one full semester for a three hour shift once a week. Student volunteers are allowed two absences during each semester. Those who have more than two absences during a semester must make up any additional absences. Non-Degree Seeking volunteers are asked for a six month commitment for a three hour shift once a week."
General Hospital Volunteer Program	VolunTEEN Program – "Hospital volunteer program for 14-17 year-old students"
1:1 Peer Support Volunteer Program	Streetlight – "The UF Health Shands Streetlight Program is a free adolescent and young adult support program for people, ages 13-25, living with cancer, cystic fibrosis, sickle cell anemia, organ diseases and other chronic or life-limiting illnesses. Streetlight seeks to: provide consistent psychosocial support and opportunities for peer socialization for adolescent and young adult palliative care patients throughout hospitalizations; adequately educate and support volunteers in their role in providing psychosocial support in healthcare; empower the coping skills and psychosocial resilience for program volunteers and adolescent and young adult palliative care patients; provide adequate emotional support and training to volunteers to help process the emotional intensities they may experience throughout Streetlight involvement; provide ongoing emotional bereavement support to patients and families of deceased patients; and to evaluate, research, and improve Streetlight program components to investigate and optimize the role of social support in improving health outcomes for frequently hospitalized adolescents and young adults."
Pastoral Care/ Spiritual Support	Pastoral Services – "The pastoral services staff at UF Health seeks to provide spiritual support for patients and their family members by providing spiritual counseling, participation in consultations, sharing sacraments and other rituals of faith and being available as supportive personas who can listen objectively to the concerns voiced to them."
Dedicated Activity Room(s) for Teens	Teen Lounge: Streetlight facilitates Teen Lounge weekday evenings from 6:30-7:30pm in the Playroom. At 6:30pm, Streetlight reserves the room for pediatric patients 13 years-old and older, engaging patients in age appropriate activities like playing video games pool, performing karaoke, making art, playing and performing music, and painting nails. Teen Lounge is an opportunity for teen and young adult patients to leave their rooms and socialize with patients and volunteers who are their age.
Hospital School Program	Hospital Homebound – "Michelle Roberts has been a Homebound Instructor with Alachua County Schools since February 2016. She came to Shands following her work as a Learning Specialist with the University of Florida's Athletic Department, where she had worked with collegiate athletes since 2008. She can see patients during admission or as outpatients when relocated to the local area for an extended period of time."

Table 4.2 Summary of Inpatient Programs Formally Offered to Chronically Ill Adolescents at 11 Children's Hospitals in the Southeast U.S., Targeting Coping Strategies, Psychosocial Factors, and/or Mental Health

	Child Life Therapy	Pet Therapy	Art Therapy	Music Therapy	General Hospital Volunteer Program	Pastoral Care/ Spiritual Support	Dedicated Activity Room(s) for Teens	Hospital School Program	Integrated Psychosocial Clinical Care Team	Media Studio/ Radio Station	Family-to-Family Mentorship Program	1:1 Peer Support Volunteer Program
Children's of Alabama*†												
Wolfson's Children's*												
UF Health Shands†												
Children's of Atlanta*												
Duke Children's*†												
Levine Children's*												
UNC Children's*†												
MUSC Children's*†												
St. Jude Children's*												
Vanderbilt Children's*†												
Hopkins Children's†												

*dedicated children's hospital † academic medical center
Note: blue shading denotes program provided

Table 4.3 Themes and Subthemes Related to Inpatient Program Support for Chronically Ill Adolescents, Families, and Providers at Shands UF Health Children's Hospital

Themes and Subthemes
Inpatient Programs Support Providers
Programs collaborate and communicate with providers
"I don't have time"
Inpatient Programs Support Families
Families need various forms of support during this time
Inpatient programs directly and indirectly support families
Inpatient Programs Support Adolescent Patients
Streetlight
Child Life
Arts in Medicine
Programs provide support beyond what clinicians offer
Inpatient Programs Enhance QoL
Programs enhance QoL
Programs help adolescents cope
Programs provide a sense of normalcy

Table 4.4 Themes and Subthemes Related to Streetlight's Ability to Address Use of Coping Skills, Psychosocial Factors, and the Mental Health Status of Chronically Ill Adolescents

Themes and Subthemes
Streetlight Helps Adolescents Cope
Streetlight keeps adolescents company
Streetlight creates a home for adolescents in the hospital
Streetlight gives adolescents attention
Streetlight helps adolescents cope with pain
Streetlight helps adolescents advocate for themselves
Streetlight Helps to Meet the Psychosocial Needs of Adolescents
Streetlight can relate to adolescents
Streetlight can adapt to meet adolescents' needs
Streetlight is non-medical
Streetlight provides company when parents cannot be there
Streetlight connects patients to each other
Adolescents describe Streetlight volunteers as their friends
Streetlight celebrates with patients
Streetlight helps with identity/independence
Streetlight helps adolescents with transitions

	Streetlight is like a family for adolescents
	Streetlight goes beyond the hospital
Streetlight Impacts Adolescents' Mental Health	
	Streetlight provides support
	Streetlight provides hope/inspiration
	Streetlight helps with depression
	Streetlight helps patients exhibiting behavioral challenges

Table 4.5 Sampling of Quotes from Interviewees, by Category

Category	Theme	Quotation
Inpatient Program Support for Chronically Ill Adolescents, Families, and Providers	Inpatient Programs Support Providers	"…you know, [they] have an office on the same unit that I do. So it's really easy to access them and for us to work together on patients."
	Inpatient Programs Support Providers	"And so I love that [they] are able to provide that additional support to the patient when I don't have unfortunately the time to do, you know because I'm so consumed, you know, working with the parent to figure out a plan to keep the family together so that … their child can receive treatment."
	Inpatient Programs Support Families	"We bring a lot of patients and families here and they get some good quality care… whatever it may be, from these interventions, that we're able to do that…a lot of other centers are not able to do."
	Inpatient Programs Support Families	"And kind of the goal of [these programs] is to have all of those resources available knowing that the family is going to need more from each piece at different times."
	Inpatient Programs Support Adolescent Patients	"[Art therapy] may be the key for somebody to open up and really express their deep fear of dying, for instance."
	Inpatient Programs Support Adolescent Patients	"[Child Life] does developmentally appropriate education with the patient to prepare them for things that they're doing to experience in order to try to reduce trauma that they might, you know, feel. They also are there to just do a lot of distraction kind of measures…"
	Inpatient Programs Enhance QoL	"I think [these programs] have a significant impact on the quality of life and even prognosis potentially. I think our focus is always going to be helping patients live as long, as comfortably as possible and if we're not addressing, you know, the spiritual needs or the psychological issues, we aren't actually going to make much progress treating the underlying condition."

	Inpatient Programs Enhance QoL	"I think it's pretty clear that just treating the actual disease process is not going to be sufficient, and I think we do a significant disservices in general in medicine, and especially, to be honest, at a center like this where we are very fixated on transplants and advancing technology and doing new and innovative procedures…we forget very easily the impact of this journey on these kids and young adults, families too."
Streetlight Addresses Adolescents' Predictors of QoL	Streetlight Helps Adolescents Cope	"[These] kids are in pain, and then having Streetlight volunteer come in, you know, to help at least distract them, you know, in that moment."
	Streetlight Helps Adolescents Cope	"They are not medical, so they really serve as a support for the patients. The things they talk about are not documented in the medical record, and in fact, are not shared with the medical team. This is a relationship that develops between the student volunteer and the patient that is protected…it's a relationship they develop that allows for the kid to have some trust in this person who is coming to see them all the time."
	Streetlight Helps to Meet the Psychosocial Needs of Adolescents	"I'm [40+] years old. There's a lot of stuff they're not going to tell me. I'm old with grey hair. They need a friend."
	Streetlight Helps to Meet the Psychosocial Needs of Adolescents	"He lived in a town near Gainesville, kind of out in the country. I went to visit him out there and there were several Streetlight volunteers out there interacting with him… it was a very light-hearted scene at his house because all of his friends were there and he was carrying on telling jokes. And two days later he died. But the whole time it was like that and he wanted it to be like that. He didn't want it to be a sad scene. And I think it wouldn't have been like that without those [Streetlight] volunteers."
	Streetlight Impacts Adolescents' Mental Health	"Sometimes it's that they're showing some behavioral stuff that I start to get worried…or they're starting to withdrawal from the team…I should ask Streetlight to see them sooner rather than later."
	Streetlight Impacts Adolescents' Mental Health	"With a depressed patient, you know, just by going in and playing video games with them can elevate their mood and help them. Does it solve the depression? No, it won't solve that. But what it does do is provide a release and it's a way for them to either talk about how they're feeling or to vent how they're feeling which they may not be that comfortable doing with certain adults in their life or even with a therapist."

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CHAPTER 5. CONCLUSIONS ABOUT THE IMPACT OF INPATIENT PEER-TO-PEER SUPPORT FOR CHRONICALLY ILL ADOLECENTS AND STRATEGIES FOR PROGRAM SUSTAINABILITY

5.1 Introduction

Based on the findings presented in Chapters 1-4, this final chapter summarizes factors for consideration among various stakeholders when faced with decisions about offering and sustaining peer-to-peer programs for hospitalized adolescents with chronic illnesses. The predictors of QoL and HRQoL identified in Chapter 2, together with the themes presented in interviews with patients and hospital providers in Chapters 3 and 4, contribute to a unified narrative illustrating the benefits of peer-to-peer programs for inpatient adolescents, family members, and hospital employees and physicians. Given decision-makers' propensity to inquire about a program's return on investment (ROI) and other metrics of success, program leaders should consider capturing key process and outcome measures, which may help decision-makers as they consider funding and sustaining these types of programs. In addition to patient experience with care, they might be interested in length of inpatient admissions and utilization of the emergency department, for example.

The findings from this research provide contributions to the existing, limited literature focused on QoL and HRQoL for adolescents in the inpatient setting, especially among those managing a chronic illness– a period of identity formation and autonomy. This research also offers implications for hospitals and physicians seeking to enhance the standard of care for adolescents with chronic illnesses, who may be especially vulnerable to social isolation given their dependency on the inpatient setting. The findings from this work should inform future efforts to improve QoL and HRQoL in the inpatient setting and to more closely examine the

needs of adolescents managing the physical and emotional aspects of living with a chronic illness.

While the benefits of inpatient program offerings are broadly discussed, the specific 1:1 peer support program model should be considered for further assessment. This work has helped to identify the benefits of 1:1 peer support provided to adolescent patients, but also to the student volunteers. Hospitals should seek to understand how student volunteers might be leveraged in the context of keeping program costs low while providing opportunities for first-hand experience and at the bedside. This contributes to the discussion on funding and sustainability considerations. This study does not attempt to compare the costs and benefits of these programs. This could be done in a subsequent study.

5.2 Summary of Overall Findings

This thesis begins with a review of existing literature to understand adolescents' predictors of QoL and HRQoL (Chapter 2). Similar predictors were organized together, and seven categories naturally emerged: 1) those associated with demographic characteristics, 2) the use of coping strategies, 3) psychosocial factors, 4) disease control/management, 5) the mental health status of the adolescent, 6) the mental health status of the caregiver, and 7) the physical environment. Subsequent analyses focused exclusively on three of the seven categories that were most actionable for hospital interventions: the use of coping strategies, psychosocial factors, and the mental health status of the adolescent. Chapters 3 and 4 focus on these three areas.

Chapter 3 summarized the inpatient program offerings of 11 children's hospitals in the Southeast US using information available on their websites, and discussions with hospital representatives, to ensure the information was accurate. While all hospitals offered a standard suite of programs (i.e., Child Life therapy, pet therapy, art therapy, music therapy, general

hospital volunteers, pastoral care/spiritual support), three hospitals offered 1:1 peer support programs.

The thesis then focuses on one program Streetlight, a 1:1 peer support program at UF Health Shands Children's Hospital. This was one of the three such programs offered among the 11 hospitals. Streetlight was chosen because it has been operational for 14+ years, focuses specifically on adolescents and young adults, and is available to adolescents regardless of their specific chronic condition(s). Analysis of interview data revealed themes about their inpatient experience generally, as well as specific themes about how Streetlight helped to address the discomforts and loneliness of the inpatient setting. Chapter 4 focused on understanding predictors of adolescents' QoL or HRQoL, but instead analyzed the perspectives of healthcare professionals, hospital administrators, and staff at UF Health Shands Children's Hospital. Their views about the role of the inpatient program offerings overlap considerably with the patients' perspectives in Chapter 3.

In addition to the focus on the adolescents there were unanticipated benefits to the staff. Clinicians and other licensed providers noted that the availability of these programs enhances their own quality of life. They described the "lack of time" and "multiple competing priorities" they encounter in the inpatient setting, often wishing they could visit with their patients longer. They also explained the compassion they have for the adolescents who sometimes face isolating hospital stays. They describe the ways in which the programs enhance the clinical care they provide and the level of comfort they feel knowing their patients are given the opportunity to socialize and interact with peers.

5.3 Implications of Findings

Information for Chronically Ill Adolescents and Families/Caretakers

This work categorized adolescents' self-reported predictors of QoL and HRQoL. In the literature reviewed, 110 different predictors were then separated into seven categories (refer to Table 3.0 in Chapter 2). In order to understand ways to potentially enhance an individual's experience living with a chronic illness, it is first important to identify the specific predictors that the individual deems most important. From there, it will be easier for the individual and their caretakers to prioritize those aspects of their daily life, and to seek out opportunities to enhance that specific area of importance.

Each of the 11 children's hospitals offered a wide variety of programs to children and adolescents in the inpatient setting. From help with school, to opportunities to interact with college students, to having a dog visit them in their room – it was clear that hospitals are committed to offering a diversity of activities. It would be important for adolescents and families to inquire about these offerings upon admission to the hospital, especially if they are facing a long inpatient stay, or perhaps multiple stays. Knowing the kinds of resources available is a great first step in thinking about how to build a care team that will work well for the individual. Often, hospital websites do not contain all of this information. It is likely that a social worker or someone in a similar role on the inpatient unit will have a vast knowledge of the offerings.

In some cases, programs are available to everyone, while others are specific to adolescents. Even in the absence of adolescent-specific offerings, it is worth inquiring about how services might be able to be tailored to adolescents. In speaking with hospital representatives, many noted their willingness to tailor offerings to adolescents, but were not sure whether adolescents or families were interested in the first place. Resources may be available, yet somewhat hidden, and adolescents and their families should inquire to learn more. The non-

clinical services provided should be considered by the adolescent and their family members to be part of their care team.

Finally, the benefits of connecting with peers in a 1:1 setting are considerable. Walking through the difficulties of adolescence while negotiating a chronic illness can be overwhelming. Close friends and peers who are compassionate and understanding are important to adolescents facing these hurdles. Whether these friends are acquired through a 1:1 peer support program, from school, from the neighborhood, or any other mechanism, does not necessarily matter. It is important, though, that their support and friendship is maintained and felt while the adolescent is in the inpatient setting.

Information for Hospital Staff/ Clinical Care Providers

Given the transitional period of adolescence, the challenges associated with managing a chronic illness, and the sometimes isolating inpatient setting, adolescents require a diverse care team to provide optimal patient-centered care. Clinicians described the ways in which inpatient programs offer services that complement their clinical care – and they described the critical role these programs play in the adolescents' care. Hospital staff and care providers realized that they should focus on collaborating more with inpatient program teams such as the Streetlight program, which often develop relationships with the adolescents that lead to insights about their behavior, their mindset, and the things they value most. This information is valuable to clinicians who do not always have the time or presence or skillset to encourage adolescents to open up in these ways. Clinicians should consider how to incorporate this information into an adolescents' plan of care. This will help to foster a more patient-centered approach than they might otherwise have developed without this information.

Clinicians and staff praised these programs for their ability to sometimes understand patients at a deeper, more intimate level than others on the care team. They even described how the programs help to enhance their own quality of life. These viewpoints should be shared with hospital administrators and decision-makers who consider many perspectives when making decisions about funding and support. Given the mounting demands on clinicians,(1,2) programs that can enhance both the quality of life of patients and providers might be considered a win-win to a hospital leader.

Peer support programs offer adolescents the opportunity to relate to others and socialize. In some cases, they are a welcome distraction from the inpatient setting – the sterile, noisy, and sometimes isolating environment. Providers may consider encouraging adolescents to engage with peers and close friends while they are in the inpatient setting.

Information for Hospital Decision-Makers

It is important to take multiple perspectives into account when making decisions, financial or otherwise, about the kinds of services provide to adolescents and their families. Aspects of time, safety, protection of patients' privacy, the availability of staff and/or volunteers, and many other factors contribute to these decisions. Given the ability for inpatient programs to enhance the QoL of patients, hospital providers, and volunteers alike, hospital leaders should carefully consider how they might prioritize and sustain these offerings.

Some adolescents and their families may place high value on the overall patient experience, which could inform their decision to return in the future or refer other families, for example. When patients have a great experience, they tend to have great satisfaction with the care they received.(3) Patient experience scores are helpful in that they: 1) provide patients' perspectives of the care they receive in an objective way that allows for comparisons across

hospitals, 2) the public reporting of these scores incentivizes hospitals to prioritize quality of care, and 3) the public reporting adds a layer of accountability and transparency for the public that may be helpful to them in their personal decision-making. Hospital leaders should consider how the programs offered to patients in the inpatient setting can positively contribute to the overall quality of care provided.

In addition to enhancing patients' QoL and HRQoL, inpatient programs were found to enhance the QoL of the hospital staff and healthcare providers. As clinicians are faced with various demands on their time, hospital leaders might consider ways to ease their burden (mental or otherwise) by offering services that "fill in the gaps" they feel they are most often unable to address. Hospital leaders should also consider ways to be sure they internally advertise these program offerings, so that clinical providers are informed about the programs they can leverage, any requirements for participation, and understand how to refer patients into the programs. In cases where certain patient populations may transition often between inpatient and outpatient care, hospital leaders may also consider opportunities to allow the patients to engage with the program in both settings, for continuity purposes. Further, as demonstrated in the Streetlight program, patients and providers both described the benefits of continuing participation in Streetlight as the patient transitioned from pediatric to adult care.

Given the reality of funding challenges and difficult decisions that are sometimes made annually about program support, hospital leaders should identify various process and outcome measures they would help them to determine whether or not these programs add value. Program leaders should be capturing this data. If programs are able to monitor their progress on an ongoing basis, and strive to meet the benchmarks defined by leadership, they may be able to be responsive to the needs of patients and providers in ways that optimize their contributions to

patients, families, and clinicians. Additionally, hospital leaders might consider how to continue to leverage and potentially expand upon the generosity of volunteers in the inpatient setting. This would not only help keep costs low, but may also provide hands-on learning experiences for students and others seeking exposure to the inpatient setting. This might be especially relevant for hospitals that are part of a broader university setting.

5.4 Impact of COVID-19 on Inpatient Program Offerings

The challenges of the COVID-19 pandemic have had significant implications for these hospital-based programs. For the last 6 months, volunteers have not been able to enter most hospitals. Adolescents, often not allowed to have visitors or engage with other patients, are perhaps more isolated than ever. In summarizing the inpatient program offerings at the 11 children's hospitals, 9 hospital representatives offered their own insights about how COVID-19 has drastically halted program operations. Social workers, Child Life staff, and others noted that because the volunteers they often rely on were not present, they were often working over-time to ensure they could stop by patients' rooms, even just briefly.(4-12) Some described feeling overwhelmed.

When the COVID-19 pandemic settles, hospital leaders should evaluate the long-term viability of inpatient program offerings at their hospitals. Given the various factors that impact the sustainability of these programs, their reliance on volunteers, and other hospital-specific factors, it will be important for hospital leaders to clearly define the goals and expectations they have for these programs.

5.5 Contributions to the Literature

The existing literature on the role of peer support in the inpatient setting is limited. Among the few articles, many are focused on peer support for adults with mental health

diagnoses.(13-15) One study found that peer support was highly valued among adult psychiatric patients, and the authors concluded that peer support should be a recognized aspect of an inpatient stay.(14) Another study among adults examined the role of peer support in the transition from treatment in the inpatient setting to the home or community setting. The findings indicated that peer support should be incorporated into inpatient treatment plans.(15)

This thesis offers valuable contributions to the limited literature examining QoL and HRQoL for adolescents with chronic illnesses in the inpatient setting. Based on adolescents' self-reported predictors of QoL and HRQoL, these analyses explored the use of coping strategies, psychosocial factors, and the adolescents' mental health status specifically.

UF Health Shands Children's Hospital, while only one children's hospital among hundreds in the U.S., provided a lens through which to examine the various offerings. The experiences of patients, clinicians, staff, and hospital leaders was instrumental in understanding the extent to which programs address predictors of QoL or HRQoL. While their viewpoints were nuanced, all of them expressed deep gratitude for the presence of these programs and their role in helping to address deeper, internal aspects of health and well-being. This work provides a unique look at the inpatient setting, specifically, which is often characterized as being isolating and uncomfortable. Recognizing and addressing their needs, beyond those associated with their chronic condition, helps to make the noisy alarms, boredom, fear, and sterile environment more manageable. The attention to this human side of medicine has a profound impact on adolescents' quality of life.

This work also illuminated an aspect of QoL for healthcare providers and hospital staff, who surprisingly described the ways in which inpatient programs help to enhance their own QoL. This research revealed that the "lack of time" they are sometimes able to spend with

patients weighs on them. They are relieved to know that programs, especially 1:1 peer support programs, are able to offer their patients more face-to-face interaction, companionship, and distraction. Provider and staff quality of life should be further examined in the context of resources and programs available to patients.

This work, and the nuances around the COVID-19 pandemic, also revealed the reliance that hospitals have on volunteers whose involvement is critical to some of these programs. Further exploration is needed to understand how hospitals can meaningfully partner with students (college or graduate school) to leverage their enthusiasm and willingness to learn more about the inner workings of clinical care. Given that their time is uncompensated, hospitals and universities may consider forming mutually beneficial partnerships.

Finally, the role of 1:1 peer support programs in the context of enhancing QoL and HRQoL for chronically ill adolescents needs further study. Streetlight at UF Health Shands Children's Hospital has garnered support from hospital staff, clinicians, families, and patients. The overwhelmingly positive reception of this program should be given close consideration among hospitals who do not offer such programs in the inpatient setting. There are opportunities to spread the Streetlight program model, or other 1:1 peer support models, at academic medical centers which are uniquely positioned to leverage student volunteers. The programs, built on similar foundations, could be tailored to meet the specific needs of the hospital and the population(s) of adolescents they serve. This thesis helped to bridge connections between the 11 hospitals in the study and provided an overview of the Streetlight model. Continued collaboration and sharing of best practices, as a first step, would be helpful for the 8 hospitals who do not offer a 1:1 peer support program.

5.6 Sustainability and Funding Considerations

In speaking with various hospital representatives in the southeast US, it was evident that they do not always have a strong understanding about how decisions are made by hospital leaders. Leaders at UF Health Shands Children's Hospital, however, were clear – among other factors, their leaders are most interested in understanding a program's return on investment (ROI) for the hospital. When probed to describe what this meant more specifically, ROI was defined in various ways. For example, a traditional ROI calculation examines the amount of money spent to run a program, in the context of how much money is saved as a result of the program. For each dollar invested, most decision-makers are interested in seeing that the program allowed them to save more than one dollar.

In its most traditional sense, however, ROI may not be the best way to examine QoL interventions. As it relates to adolescents with chronic illnesses, the programs they are offered may have little impact on their length of stay or their health outcomes (both of which may be expensive for the hospital), but may help to improve their satisfaction with their care, for example. Hospital leaders may want to decide how satisfaction can be quantified if the use of an ROI model is desired. Some hospital administrators might find other non-financial factors useful to quantify.

Among those interviewed at UF Health Shands Children's Hospital, some described how hospital leaders, if not already, should consider the perspectives of patients, families, and clinicians in order to make informed decisions about the future of programs. They felt the stories and personal experiences would be compelling and would shed light on some of the uncomfortable and lonely realities of the inpatient setting. They also brainstormed various metrics that hospital leaders might consider. These include the number of patients seen by a program, QoL survey results before and after interacting with a program, and survey data from

clinicians who had referred patients to a program, for example. Further investigation around a possible dose effect would help to reveal whether more encounters with peers further enhanced quality of life. These findings would have potential implications for offering 1:1 peer support throughout the day (i.e., more than 3 hours), offering extended support in the outpatient setting, and possibly even via online platforms.

While all of the hospitals in this sample explained the dedication of their leaders to ensuring the sustainability of inpatient programs, most also explained that the programs at their hospitals largely rely on philanthropic support and grant funding to operate year-to-year. Given the financial realities facing hospitals, especially in the wake of the COVID-19 pandemic, it is understandable that hospital leaders are faced with difficult decisions about how to allocate funds. Innovation, collaboration, and the ability to leverage volunteer resources is critically important in the continued funding and long-term sustainability of inpatient support programs. Interviews with the children's hospitals revealed their willingness, excitement, and enthusiasm for continued study in this area. There should be no hesitation to engage with others in similar roles across hospitals to ask questions, exchange stories, and offer workflows, policies, volunteer requirements, and other information that could be leveraged to pilot a 1:1 peer support program with minimal startup effort.

5.7 Policy Implications

This thesis presents implications for improving quality, patient-centered care for patients with chronic illnesses, who may face long periods of time in the inpatient setting. The impact of social isolation on QoL, HRQoL, and even health outcomes should be carefully considered by hospital leaders, decision-makers, and those at the policy level. Most hospitals are optimized to care for acute illnesses,(16) but patients with chronic illnesses may have additional needs,

especially related to the use of coping skills, psychosocial factors, and mental health status. In order to optimize standards of care for adolescents with chronic illnesses in the inpatient setting, policymakers need to consider how care delivery systems prioritize the predictors of QoL and HRQoL. Standards of care for individuals with chronic illnesses should include specific recommendations for the inclusion of 1:1 peer support, when possible. The availability of student peers, whose compassion drives them to volunteer, should be leveraged whenever possible to create a favorable scenario for adolescent patients and students alike. Hospitals should be expected to continuously monitor chronically ill adolescents' QoL and HRQoL using standardized tools (i.e., a clinical vital sign). These scores, and related notes from the care team, should be documented in the electronic health record as part of the patient's care plan. This information should be analyzed in aggregate, by hospital unit or diagnosis/condition, at least quarterly, in order to understand possible predictors of adolescents' QoL and HRQoL.

The importance of social interaction, companionship, and peer support among adolescents with chronic illnesses is addressed in the training requirements for medical professionals in the U.S. by the Accreditation Council for Graduate Medical Education. As illuminated in this qualitative study, the training is critical for medical professionals. The quality of the training provided may vary. Colleges and universities might consider whether they can provide additional opportunities for students to gain first-hand experience in the inpatient setting. The responsibility of caring for adolescents with chronic illnesses should require deep knowledge of and exposure to the psychosocial complexities they face.

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APPENDIX

Interview Guide

Let's begin the interview. Feel free to ask me to clarify anything I ask if you do not understand.

1. Work at UF Health / Involvement with Patient Programs

(Note: These questions will be uniform across all interviewees, regardless of role)

- Can you please describe what your usual day looks like, in terms of the nature of your work?
- Can you please describe your understanding of the various patient support programs offered to adolescents at the hospital?
    - Do you believe there is a need for these programs? If so, can you please discuss that "need"? Who has the "need"?
    - What are these programs called?
    - What do these programs seek to do?
    - What do the programs have in common? How are they different?
    - What are UF Health's greatest strengths, in terms of supporting patients in the inpatient setting?
    - Do you think UF Health has any gaps in inpatient support programs? If so, what are they?
    - Is there anything else you would like to share with me about your work at UF Health or your involvement with patient programs?

Now, I would like to focus more specifically on the Streetlight program. These questions will be specific to that program. This is not a "test" in any way – just tell me what you know about the program.

2. Understanding of Streetlight

(Note: These questions will be uniform across all interviewees, regardless of role)

- Can you please tell me about the Streetlight program, including how you learned about it?
- From your perspective, what does Streetlight offer patients?
- How does Streetlight compare with other services available to patients at UF Health? At other children's hospitals?
- What do you know about the Streetlight volunteers?

- What do you know about the Streetlight staff?

Depending on responses, follow-up questions may ask for more detail, or for the interviewee to share examples. "I heard you say….Can you tell me more about…?"

3. Program Dimensions

(Note: The wording of these questions may vary slightly across interviewees, according to their role)

- Earlier, I asked you what you thought Streetlight offered patients. Do you think there is something different, or additional, Streetlight *should* offer? Do you think there are things Streetlight *shouldn't* offer?

For providers/clinicians:

- Does Streetlight offer the same or different services than other UF Health providers? Can you please explain and provide examples, if possible.
    - *If providers offering same services*:
        - What is your impression of other UF Health providers being able to address psychosocial needs of adolescents?
        - What is your impression of Streetlight volunteers being able to address psychosocial needs of adolescents?
    - *If providers offering different services*: Do you see the Streetlight services as complementary to the services offered by other providers? Please describe.
- Have you ever referred a patient to Streetlight?
    - If yes:
        - Can you please tell me about your decision to make the referral?
        - Have you, or would you, recommend other adolescents to Streetlight?
        - Have you, or would you, *not* recommend other adolescents to Streetlight? Can you please explain that to me?
- Can you tell me about a time you saw a patient interact with a Streetlight volunteer?
- Do you have specific impressions about the program, positive or negative, you would be willing to share?
- If this program were to be replicated at other children's hospitals, what changes, if any, should be considered?

For hospital leaders/administrators:

- Going back to a question I asked you earlier -- Are there any other programs that offer similar services to adolescents in the inpatient setting at UF Health? If so, can you tell me about your impression about those services and whether or not they overlap with Streetlight?
- Thinking about hospital volunteers now -- Can you tell me what you know about how hospital volunteers are selected and trained? What is your impression of the training?
- Can you tell me what you know about how Streetlight volunteers are selected and trained? What is your impression of the training?
- Can you tell me about a time you saw a patient interact with a Streetlight volunteer?
- Do you have specific impressions about the program, positive or negative, you would be willing to share?
- If this program were to be replicated at other children's hospitals, what changes, if any, should be considered?

4. Sustainability

(Note: The wording of these questions may vary slightly across interviewees, according to their role)

- Can you explain what you perceive to be UF Health's commitment to or investment in Streetlight, financially or otherwise?
- Since it began in 2006, Streetlight has been supported primarily through private donations.
    - How would you respond to potential news that Streetlight would not continue?
    - How do you think other hospital providers and staff would respond?
    - How do you think families and patients would respond?
- How do leaders at UF Health make decisions when considering what kinds of patient support programs to offer? What kinds of information are useful to them?

5. Conclusion

- Is there anything else you would like to tell me about Streetlight that I did not ask about?